State Title V Block Grant Narrative

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Sections 5.4 – 5.7, containing standard forms and detailed descriptions of national and State performance and outcome measures, are not included in this PDF. Data from these sections can be viewed in interactive formats on the Title V Information System Web site (http://www.mchdata.net).

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I. COMMON REQUIREMENTS FOR APPLICATION AND ANNUAL REPORT
1.2 Face Sheet

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1.4 OVERVIEW OF PUERTO RICO

Geography and Population Characteristics

Geography: Puerto Rico is a Caribbean island, the smallest of the Greater Antilles. It is located between latitudes 17^0 50' and $18^0$30'; and longitudes 65^0 13' and 67^0 50'. The climate of the Island is a tropical maritime one, with an average high temperature of 86^0 F and a low average temperature of 66.9^0 F. The Atlantic Ocean borders the north of Puerto Rico and the Caribbean Sea borders the South Coast. The island of Puerto Rico is 100 miles long and 35 miles wide for an approximate area of 3,500 square miles.

Towards the east of Puerto Rico, across the sea, there are two small islands that belong to Puerto Rico, Vieques and Culebra. The population of these two islands travels to and from the islands in boats or small planes in order to access secondary, and tertiary health care as well as other human services.

The Dominican Republic, another of the Greater Antilles islands, is located west of Puerto Rico. Our proximity allows for mutual tourism and the sharing of economic and cultural resources. However, it also allows the entry of a significant number of illegal immigrants affecting our health care systems as well as our health indicators.

Geographically, the Island is divided in 78 jurisdictions known as municipalities, each headed by a mayor who is elected every four years. The largest municipalities in Puerto Rico are San Juan, the capital; Bayamón, Carolina, Caguas, Arecibo, Mayagüez and Ponce.

Population: Puerto Rico is one of the most densely populated areas of the world. According to the 1990 Census Bureau, the total population of the Island was 3,522,037. This represents a population density of 1,025 inhabitants per square mile. Over 71% of the population resides in the urban areas, where an overwhelming concentration of people reaching figures as high as 9,314 persons per square mile are found.

More than 37% of the population was comprised of children and adolescents; over 44% were under 24 years of age; 23.5% represented women of childbearing age (WCBA, 14 - 44. years). The male to female ratio was 94:100; the average number of persons per family was 3.7. Twenty-three percent of all households were headed by single women; and 51% of all female householders with no husband present, lived with children under 18 years of age.

The estimated population trends indicate that the population will increase close to twenty percent (18.6%) from 1990-2025. It also shows a decrease in the proportion of age groups under 24 and an increase in the proportion of persons over 60 years of age.

In 1998, the Planning Board of the Government of Puerto Rico estimated a total population of 3,833,482 persons. This figure represents an increase of 8.0% as compared with the 1990 USA Census. Women in their reproductive age (15-44 years) and children (0-19 years) accounted for, 2,028,128 individuals of the total population (52.9%).

Race and Ethnicity: It is important to highlight that Puerto Ricans are not classified by race. The most significant ethnic groups residing on the Island are Dominicans and Cubans. Most Dominicans are concentrated in the metropolitan areas close to San Juan. A significant number of Dominicans are undocumented. In 1998, the U.S. Immigration Agency reported 7,540 new lawful permanent residents' aliens and approximately 37,700 illegal residents in the Island. Puerto Ricans, Dominicans and Cubans have a Hispanic background. Spanish is the official language of the Government of Puerto Rico. In addition, a significant proportion of Puerto Ricans can also communicate in English quite well.

Education: According to the Census Bureau the illiteracy rate was close to 10% in 1990. This is unexplainable when we consider the wealth of the public and private education systems available in Puerto Rico.

Currently, there are 1,547 public schools with 613,083 active students (1999-00). The higher education system consists of the University of Puerto Rico located in Rio Piedras, a San Juan area; and its regional colleges located in Arecibo, Bayamón, Carolina, Cayey, Humacao, Mayagüez and Ponce. Its Medical Sciences Campus includes the Puerto Rico School of Medicine and the School of Public Health located within the complex of the Puerto Rico Medical Center.

Parallel to the public education system is the private education sector. It also provides elementary, high school and college education. More than 55 institutions of higher education had been established in Puerto Rico since 1980. These include three (3) private schools of medicine located in Bayamón, Caguas and Ponce.

However, data from 1998 reflects that the number of women who achieved less than high school education at the time of delivery amounted to17,057 (28.2%), compared with 21,009 (31.3%) in 1995. In spite of the 18.8% decrease, it continues to be a significant number of women with poor educational attainment that places them at social and economic disadvantages. It has been found that women with less formal education have higher smoking and substance abuse rates, thus contributing to increased infant morbidity and mortality rates.

Income and Poverty: According to the 1990 Census, 58.9% of the population, 66% of children under 5-17 years and 55.5% of all families lived below the poverty line. On the other hand, in 68 of the 78 municipalities, 50% of the population lived below the poverty level. The per capita income was $4,177 in 1990. The per capita personal income increased to $9,930 by 1999 but, it is still under the U.S. and the Mississippi averages. The unemployment rate in February 2000 was 10.5, in contrast to 3.9% in the U.S. (April 2000, El Nuevo Día). Among adolescents and young adults unemployment is even higher, creating a fertile environment for criminal activities and other social problems.

TABLE 1
PUERTO RICO UNEMPLOYMENT RATE:
ADOLESCENTS AND YOUNG ADULTS, FEBRUARY 1995 – 2000

	16-19 years	20-24 years	25-34 years	PR	USA *
Feb. 1995	31.9	21.7	Not available	13.0	5.4
Feb. 1996	38.7	20.4	15.7	13.0	5.5
Feb. 1997	28.0	21.9	14.2	12.7	5.3
Feb. 1998	32.8	25.3	15.8	13.9	4.6
Feb. 1999	36.7	23.2	13.6	12.5	4.4
Feb. 2000	23.7	18.6	10.3	10.5	4.1

Source: Department of Labor and Human Resources; Bureau of Labor Statistics, Labor Force Statistics Division.
*Note: *USA Data for the 50 states*

In FY 1999, the number of beneficiaries of the Nutritional Assistance Program was 1,139,397 compared to 1,480,547 in 1992. This is represents a decrease of 23%. The downward trend in the number of the beneficiaries of the Food Stamp Program would be the result of an increase in the per capita income and the effect of the implementation of the Puerto Rico Welfare Reform Act (PRWORA). However, in Puerto Rico, one out of three persons still continue enrolled in the Food Stamp program.

Another indicator that reflects the socioeconomic status is the number of individuals enrolled in the Temporary Assistance to Needy Families (TANF) program. During FY 1998-99, there were 76,146 families for a total of 150,427 individuals participating in the TANF program. Nearly 63 millions dollars ($62,958,364) were invested in assistance for these families.

Private Sector Resources: Significant improvements have been made in the economic conditions since the late 1940's. In the early 1990's, manufacturing was the leading economic activity. Other important sources of income are government, commerce, and tourism. Among the major manufactures are pharmaceuticals, industrial machinery, printed materials, rubber and plastics, metal items, precision instruments, timepieces, footwear and alcoholic beverages. Agriculture is another source of income. The most valuable crop is coffee, followed by vegetables, bananas, plantains, pineapples and other tropical fruits. Dairy products, poultry, beef cattle and calves are also important sources of income. The warm year round climate in Puerto Rico and its abundant sunshine and beautiful beaches promote the tourism toward this precious Island.

Vital Events (1998)
Births: **Figure 1** summarizes the vital events in Puerto Rico as reported in the latest vital statistics report of 1998. The estimated population was 3,833,482 inhabitants.

A total of 60,518 live births were registered; 99.8% occurred in hospitals. Very few live births (121) occurred at home or other places. The natality rate was 15.8/1000 inhabitants as compared to 18.0/1000 in 1998, a decrease in 12.2 percent. The cesarean sections rate climbed to 35.1 percent.

Marriages and Divorces: The rate of marriages was 9.3/1000 and divorces occurred at a rate of 5.2/1000 inhabitants. The divorce rate showed an increase of 5.8% as compared with 1995 data (4.9/1000).

General Mortality: Total deaths amounted to 29,990, a rate of 7.8/1000 persons. The leading causes of death occurred in the following order: (1) Heart Disease (20.1%); (2) Cancer (16.5%); (3) Diabetes (7.7%); (4) Cardiovascular (4.7%); (5) Hypertensive Disease (4.7%); (6) All Accidents (4.6%); (7) Obstructive Pulmonary Disease (4.6%); (8) Pneumonia & Influenza (4.4%); (9) Homicides (2.7%); and (10) Liver Diseases and Cirrhosis (2.2%). It is important to underscore that AIDS moved from rank number 6 in 1995 to the 12th position in 1998.

Infant Mortality: This topic will be discussed in the section of needs assessment.

The Health Care Delivery Environment: In just six years, the health care environment of the Government of Puerto Rico has been radically changed. The environment for delivery of maternal and child health services has being refocused as a response to the changes of the entire system of care. Therefore, an understanding of the changes that are occurring in the health system of Puerto Rico is important to providing the context of the MCH/CSHCN programs priorities and activities.

Traditionally, the health care system in Puerto Rico has been divided into two parallel systems: public and private sectors. The public sector served people of low economic resources through a regionalized health care system in which the portal of entry was the primary level. This system was responsible for addressing all health care needs for almost half of the population with scarce resources. On the other hand, the private health care system served 42% of the population who paid out of pocket or through third party payers.

After enactment of Law No. 72 on September 7, 1993, an aggressive Health Care Reform (HCR) was launched in Puerto Rico. The HCR attempts to bridge the gaps in services between the public and private sectors. At the same time, one of its goals was to privatize the public health care systems through renting or selling its facilities. In addition, the Department of Health established its core functions of public health following the recommendations of the Association of State and Territorial Health Officials (ASTHO). The Department of Health instituted as its top priority the promotion and protection of health.

As of July 1st, 2000, the HCR was implemented in all the Island. By December 31, 1999, close to 1.8 million residents were enjoying the benefits of the government insurance plan. The second phase of

the HCR includes the offering of the GIP to public employees on a voluntary basis. By July 1st, 2000, public employees were given the option to be enrolled with their dependents in the GIP at no cost to them. However, those employees who don't want the GIP will continue with their preferred health care plan as usual**. Figures 2 and 3** demonstrate a shift in the proportion of Medicaid to GIP while the percentage of the population with private health insurance remains more or less the same.

The Puerto Rico's Health Care Reform introduced a new model of health care delivery to uninsured patients, aimed at providing health care to all low income residents, offering quality services and eliminating existing or potential barriers to the access of primary, secondary, tertiary and supra-tertiary health services.

The success of the Health Reform has been possible due to the extensive collaborative effort at the municipal, regional and state levels. The personal interest that the Governor of Puerto Rico has in this project, as a pediatric surgeon and public health professional, is of great importance for this endeavor. Without his enthusiastic initiative, this project would not have been possible. This collaboration provides the necessary components to ensure satisfaction among the population and demonstrates a genuine effort on behalf of the current administration to improve the quality of life of our citizens.

An expanded coverage of health care services was one of the most significant accomplishments of our Health Care Reform. It includes the following services: Preventive Ambulatory Services, Surgical, Hospitalization, Maternity, Mental Health, Prescription Drug Services, Dental, Emergency Room, General and Drug Rehabilitation, Ambulance (Ground and Air), Laboratory testing, X-Rays and Catastrophic Coverage including AIDS, TB, Cardiovascular, Cancer, Neonatal and Intensive Care, among others.

This new approach of expanded health services complies with the basic principles of the Health Care Reform, which are to:

1. Eliminate the public and private sector disparity and discrimination in health care;
2. Guarantee access to quality health care to all residents;
3. Have freedom for selection of a primary health care provider;
4. Increase the efficiency and productivity of the health care industry through a competitive mechanism;
5. Improve the quality of services;
6. Modify the role of the Government in the areas of health promotion and disease prevention; since participants have the option of selecting the health care site and provider, these principles enhance and guarantee universal access to adequate health care services.

Who benefits from the Government Insurance Plan (GIP)?

- Medicaid Beneficiaries
- Veterans (Non service connected)
- Medicare Beneficiaries (Part A and B)
- Police Officers and their families

C Public Employees and their direct dependents

An important strategy of the Health Care Reform is the transfer to the private sector of the diagnostic and treatment centers (DTC's) and the public hospitals. The first step of the privatization process was the leasing of the public health facilities located in the areas where the Health Reform had been implemented. After a request for proposal and its comprehensive evaluation, a contract is signed between the renter and the Government.

As the health facilities are privatized, physical improvements are made. The scope of the quality of services is a top priority for privatizers. A visit to these facilities demonstrates that the privatization process has benefited all parties involved. Health services that were not provided prior to the implementation of the health care reform are now possible through the privatizers. Another aftermath of the privatization process is the decrease of the bureaucracy processes.

The second step of the privatization process is the sale of the public health facilities. The Government had to amend or legislate, as for example, State Law 31, which expedites and facilitates the sale of the government owned DTC's and hospitals. The facilities are now sold to private for profit and non-profit organizations. The first request for proposals was announced in May 1997. As of June 2000, the Department of Health had sold 50 health facilities, including 8 hospitals. There are still 10 other facilities rented or administered by the Department of Health.

In order to comply with the core functions of the Department of Health, the categorical programs coordinate efforts with the private sector. These providers are seen as partners in the Health Care Reform and we are very pleased with the ongoing progress of these coordinated efforts.

One of the indicators that can be used to demonstrate the success of the Health Care Reform is the annual cost per patient. Until 1992, this index had shown a dramatic increase. From 1985 to 1992, it increased over 250%. After 1993, it has been consistently decreasing year after year.

Another indicator of the Health Care Reform success has been a marked increase in the availability of health care providers. For example, before the Health Care Reform, 1,147 physicians served the medically indigent population residing in the Health Reform areas. This number increased to 4,644, which represents a growth over 400 percent. A similar trend is observed in other groups of health care providers and in primary care centers, pharmacies, laboratories, and hospitals, among others. (Table 2)

TABLE 2
NUMBER OF HEALTH CARE PROVIDERS AND FACILITIES
BEFORE AND AFTER THE HEALTH REFORM IMPLEMENTATION
PUERTO RICO, MARCH 2000

Health Care Provider/Facility	Before	After	% Change
Physicians	1,147	4,644 [1]	404.9
Dentists	110	743	675.5
Primary Health Centers	85	300	352.9
Pharmacies	86	753	875.6
Hospitals	9	42	466.7
Laboratories	63	491	779.4
X-Rays	9 [2]	151	1,677.7

1. Primary Physicians 2,970; Specialist MDs 1,674.
2. Only at hospitals.

An additional important strategy is the transformation of the Department of Health from a disease-oriented agency to one that encourages health promotion and protection programs and primary, secondary and tertiary prevention programs within the context of a comprehensive continuum of public health services.

Studies and surveys conducted by our agency and the "Administración de Seguros de Salud de Puerto Rico" (ASES) or the Puerto Rico Health Insurance Administration, show a high percentage of satisfaction among the clientele. Close to nine out of 10 (87.8%) of those interviewed reported being satisfied with the new service system. This finding has encouraged all of us, because it is the best index of the success of HCR as a social justice project. (See **Figure 4**)

Among the reasons given by beneficiaries to preferring the new system in contrast to the traditional system are:

1. The GIP is better than the services we had before.
2. The availability of more and better services.
3. There is more accessibility to medications and better pharmacy services.
4. There is better attention at the health service centers.
5. Services are free or require low co-payment.

State Health Agency's Current Priorities or Initiatives: In addition to the GIP, which is mainly implemented by ASES, and as a result of the HCR, the Department of Health has modified its role and approaches in pursuing the optimal health of the population. The Department of Health has been

emphasizing in the core functions of public health that include needs assessment, policy development and assurance. It has also modified its role of a disease-oriented agency towards one of health promotion, disease prevention and health protection of the population at large.

A Strategic Action Plan has been developed which is divided into three major phases: planning, implementation and evaluation. A variety of initiatives or programs have already been implemented to address the health needs of the population at large or to segments of the population with special needs. These initiatives include, but are not limited to:

- **The Healthy Community Program ("Programa de Municipios Saludables") -** The mission of this program is to raise the health status of the diverse population groups residing in each of the municipalities. The strategy to develop this concept and reach its goal involves a comprehensive assessment of the needs and capacities of the community. Challenges and opportunities to improve the health of the community are identified. Beginning with the Mayor of the municipality, all community leaders are brought to the table to design a concerted action plan to address identified health needs. Currently, the Healthy Community program has been implemented in 10 municipalities. In each of these Healthy Communities several health promotion and disease prevention programs are implemented responding to its specific identified needs and the available resources. Among these programs we can mention the Chronic Disease Prevention Program, called Carmen Project (Conjunto de Acciones para Reducir la Mortalidad por Enfermedades No Transmisibles), the Wellness Center, the Diabetes Mellitus program, From Neighbor to Neighbor, Trip to the Supermarket, etc.
- Two new assessment studies used to determine prevention strategies are:

  - **The Behavioral Risk Factors Survey**, which is a national CDC-sponsored cross-sectional yearly study designed to identify health trends, lifestyles and behaviors among Puerto Ricans. Four questions addressed to identifying asthma morbidity were added this year.
  - **The HIV Prevention Needs Assessment**, an Islandwide study of a large sample of high-risk populations. The purpose of the study is to identify the health needs of these groups. The results are used to design custom-made HIV/AIDS/STD primary and secondary prevention programs.

- **The Basic Sample Survey –** This is an annual representative probabilistic survey of approximately 3,000 personal interviews that looks for sociodemographic characteristics, service utilization, prevalence of health conditions and the reasons for work absenteeism, including hospitalization and ambulatory conditions.
- **The Distance Learning (An Interactive Education program)** - To educate and train private and public health professionals through nine transmission centers located at regional hospitals Islandwide by means of telecommunications.

- **Rape Victim Centers -** The opening of four centers to assist rape victims ("Centro de Ayuda a Víctimas de Violación") and the expansion of services to assist domestic violence victims across the Island.
- **The Implementation in Hospitals of the Health Policy on Breastfeeding** - This policy encourages private and public hospitals to promote breastfeeding practices among their patients. A Steering Committee has been established at the state level to promote the implementation of breastfeeding. The MCH Nutrition Coordinator leads this committee. The Committee has already developed a five-year plan aimed at increasing the breastfeeding rate in Puerto Rico.
- **Puerto Rico's Safe Kids Coalition -** A multi-sectorial organization. Its goal is to reduce unintentional injuries among children and adolescents.
- **The Folic Acid Campaign** - A long-range collaborative campaign, which includes a broad array of organizations, private and public agencies and is aimed at decreasing the number of infants with neural tube birth defects.
- **The Congenital Anomalies Registry** – It has already included the registry of NTD and cleft lip/palate. Down syndrome, gastroschisis, clubfoot and other common orthopedic conditions are the next conditions to be included.
- **The State Systems Development Initiative (SSDI) –** It was launched in 1993 to facilitate the development of State level infrastructure which would, in turn, support the development of systems of care at the community level. The SSDI program is designed to complement the Title V (Maternal and Child Health Block Grant Program) and to combine the efforts with the State Maternal and Child Health (MCH) and the Children with Special Health Care Needs (CSHCN) Programs. The SSDI Program focuses on the Title V Block Grant needs assessment; and monitoring of performance, outcome measures and MCH health status indicators.
- **The Healthy Start Project with its Home Visiting Program-** Its goal is to reduce the infant mortality rate through a home visiting program for at risk pregnant women and children under 3 years of age. The Puerto Rico Healthy Start Project replicates the care coordination/case management model by means of trained registered nurses. In the public health arena, one of the best indicators of the health status of a country is its infant mortality rate. Our efforts have improved this indicator. A net downward trend has been reported since 1993 (**Figure 5**). Our goal for the Year 2000 is an infant mortality rate of 8.5/1,000 live births. It is expected that the Home Visiting program will be an essential component to achieve the stated goal.
- **The Title V Evaluation and Monitoring Section –** This section of the MCH Division has re-established the Infant Mortality Epidemiological Surveillance System for Puerto Rico ("SIVEMI") and the "Estudio de Salud Materno Infantil" (ESMIPR). This is a customized PRAM survey carried out by means of the resources of Title V. The Title V Evaluation and Informatics Section, in conjunction with the SSDI Project, monitors all the performance and outcome measures. In December 1999, two scientific abstracts were presented at the "Annual Maternal, Infant and Child Health Epidemiology Workshop" to document part of our efforts analyzing Puerto Rico MCH data. We were honored with the 3rd prize in the poster section.

- **The Asthma Coalition** –Is an initiative based on a collaborative, multidisciplinary model including agencies, private and public organizations, universities and parents to reduce the morbimortality due to Bronchial Asthma in children in PR. The Pediatric Pulmonary Program is located at the PR Cardiovascular Hospital and has served around 100 children since August 1999.
- **The AIDS Affairs Program** – The AIDS Affairs Program provides prevention and treatment to the population at large. In 1993, 2,697 AIDS cases were reported, and by 1994 this number decreased to 2,358. In 1999, 855 new cases were reported, for a decrease of 2,000 cases as compared with 1993. There is a 68% downward trend for the seven-year period. A triple therapy protocol has been possible through federal funding. (**Figure 6**)

  A decrease in pediatric AIDS cases has been observed during the past years (**Figure 7**). During 1999, only one HIV+ child was born among the 83 pregnant women treated according to the protocol.
- **The Oral Health Prevention Program** - Under the Health Care Reform, oral health services are included in the benefit package. Patients are not required to obtain a referral to get oral health services. They can access oral health whenever they want and with their preferred dentist. In addition, the Assistant Secretariat for Oral Health has a very active prevention program throughout the Island. Preventive encounters show an increasing tendency since 1994, except in 1999 as a result of Hurricane Georges. (**Figure 8**)
- **The Immunization Program -** The Puerto Rico Government established compliance with the Hepatitis B vaccination as a requirement for school admission, for those born from 1991 on, and those who are 13 years of age. By 2000, all adolescents from 13 to 18 must be immunized against Hepatitis B. Puerto Rico has achieved an immunization rate of 93.7% in children through 2 years (2000). Puerto Rico has been the jurisdiction with the highest percent of immunized children in the nation for three consecutive years. (**Figure 9**)

The evaluation process is a continuous cyclic activity that starts with the planning, development and implementation. This will allow us to assess the immediate impact and the long-term effects in improving the health of the population at large through the different programs previously described.

The Welfare Reform: Concerning the impact of the welfare reform, it is expected that this will not negatively affect the unique initiative of HCR that is being implemented in Puerto Rico. Even with the cap imposed by the federal government to the allocation of the Medicaid program of Puerto Rico, it was planned that by Year 2000 all municipalities will be in the Reform. This goal was achieved by July 1st, 2000. Over 80% of the funds used to cover the government insurance plan for eligible clients come from the partnership among state and local municipalities.

Puerto Rico CHIP Program: The PR CHIP plan was finally approved in June 1998. Through this program, Puerto Rico receives $9.8 million dollars during the first year and $32 million in 1999. Based on the current premiums, this amount helps to cover about 150,000 uninsured and underinsured children, between 101-200% poverty level. Puerto Rico shall continue allocating its

State funds to achieve the goal of the HCR aimed at assuring a health insurance plan to all residents in the Island irrespective of their age.

Current MCH Priorities and Initiatives: As already described, in 1994, the Government of Puerto Rico began implementing an aggressive HCR, under which the public service delivery system is being incrementally privatized in all the island's health regions. Under the reformed system, responsibility for providing personal health services to low income and underinsured populations is being transferred from the public to the private sector and all care is delivered through managed care service delivery models. The Reform was first implemented in the sub-region of Fajardo and moved very quickly to other areas. Currently, the HCR has been implemented Islandwide (**Appendix 1**).

The reformed system replaced an extensive public health infrastructure that traditionally served low income and uninsured residents of Puerto Rico. The PRDH historically functioned as the predominant provider of personal health services for these populations, operating an extensive network of primary care diagnostic and treatment centers (86) and hospitals (9) reaching all corners of the Island.

The PRDH has delegated the provision of direct care services to the private sector, through contracts with health insurers, while maintaining the non-delegable core functions of public health. These functions include needs assessment, policy development, assurance and training of health professionals. The Department of Health has also retained the administration of certain federal programs and special services such as the WIC program, Medicaid, services for persons with AIDS and the MCH program, among others.

Considering the above context and the mandates of Title V, the MCH role was refocused to assure, at this time of transition, that the most vulnerable population does not fall through the cracks of the evolving system. The MCH struggles to enable women, infants, children, adolescents and CSHCN to receive high quality and comprehensive services across a system that is now more complicated. Responding to this need, a new program was designed and is being incrementally established in municipalities under the HCR. This is the Home Visiting Program that serves pregnant women and children less than 3 years of age with multiple social and health risk factors.

Early intervention services for children with developmental delays from zero to 3 years of age continue to be provided directly by the Department of Health. The child count on December 1999 accounts for a total of 2,978 infants and toddlers served, representing approximately 1.6% of the population 0 to 3 years of age. The Pediatric Centers located in each of the seven (7) health regions continue to provide direct specialized services to the special needs population. In December 1999 the Department of Health initiated a contract with Health Care Consulting Services, an external accounting firm, aimed to oversee the billing of the Pediatric Centers to the insurance companies, including those under the HCR. Reimbursement from the private sector for services rendered that are included in the benefits package of the government insurance plan (GIP) are used to support services; it also facilitates the provision of hearing aids, braces and orthotic devices now funded by Title V as complement to the GIP benefits.

The MCH program has an Advisory Board, which is a multi disciplinary and intersectorial group of professionals and representatives of the MCH population (**Appendix 2**). They are very committed and knowledgeable of MCH issues. The Advisory Board has been a fundamental piece in providing input regarding new priorities and strategies to address the needs of the MCH population within the emerging new HCR environment. Most of their recommended strategies are considered in the action plan aimed at improving the health and well being of the MCH population, including CSHCN.

1.5 THE STATE TITLE V AGENCY

The Department of Health of Puerto Rico (DHPR) is the umbrella agency assigned in Article IV, Section 6 of the Constitution of the Government of PR responsible for all matters pertaining to public health, with the exception of maritime quarantine. The Secretary of Health is appointed by the Governor of Puerto Rico and confirmed by the legislature. The Department of Health organizational chart is included in **Appendix 3**.

1.5.1 STATE AGENCY CAPACITY

1.5.1.1 Organizational Structure

The Administrative Order No. 99, signed by the Secretary of Health on July 28, 1995, determines the current organizational structure of the agency (**Appendix 3**). It comprises 7 secretariats, 14 offices, 3 programs and administrations, the General Council of Health and the Corporation of the Cardiovascular Center of PR and the Caribbean, all responding directly to the Secretary of Health, as well as three offices which respond to the Sub-Secretary of Health.

A. Secretariats:

1. Secretariat for Auxiliary Services
2. Secretariat for Planning, Evaluation, Vital Statistics and Information Systems
3. Secretariat for Health Promotion and Protection
4. Secretariat for Regulation and Certification of Health Facilities
5. Secretariat of Nursing Affairs
6. Secretariat of Environmental Health
7. Secretariat of Oral Health

B. Offices and Programs

1. Office of the Secretary of Health
2. Office of Legal Affairs
3. Office of Federal Affairs
4. Communications Office
5. Office of Special Projects
6. Office of Human Resources
7. Office of Internal Audit
8. Fiscal Affairs Office
9. Medicaid Program

10. Correctional Health Program
11. Demographic Registry
12. Laboratory Institute
13. Congress of Quality of Life
14. WIC Program

C. Independent Administrations Created by Law

1. Health Services Facilities Administration: Law No. 26, November 13,1975
2. Health Services Administration of Puerto Rico: Law No. 66, June 22, 1978. This was abolished by Law No. 187, August 7, 1998.
3. Administration of Mental Health and Anti Addiction Services: Law No. 67, August 7, 1993

D. General Health Council: Law No. 23, June 23, 1976

E. Corporation of the Cardiovascular Center of PR and the Caribbean: Law No. 51, June 30, 1986.

In addition to the components listed above there are three other offices under the direction of the Sub-Secretary of Health. These are the following:

1. Office of the Sub Secretary of Health
2. Health Professionals Education Office
3. Office for Regulation and Certification of Health Professionals

The Department has two main functions: Normative and Administrative or Operational. The normative function is performed by Secretariats, Offices and Programs, which respond to the Secretary of Health, (see **Appendix 3**). The Health Services Facilities Administration ("AFASS") established by Law in 1975 was abolished in August 1998. Presently, the Department of Health, through its Secretariats and categorical programs, assumes the operational function also.

The Puerto Rico Department of Health provides a three-level regionalized system of health services. The Department divides the 78 municipalities of the island of Puerto Rico into six Health Regions: Arecibo, Bayamón, Caguas, Mayagüez, Metropolitan and Ponce, and three Sub-Regions: Aguadilla, Fajardo and Humacao (**Appendix 4**). The MCH program agreed to consider the municipality of San Juan as a health region for resources allocation purposes. Each health region has a Regional Director. This regionalized health system provides a common framework for the coordination of a full spectrum of comprehensive care for the Maternal and Child population including CSHCN.

Puerto Rico's Title V program is administered by the Assistant Secretariat for Health Promotion and Protection (ASHPP), see **Appendix 5**. The Secretariat is also responsible for conducting needs assessment, developing policy, ensuring quality, and coordinating health services for women of reproductive age and children, including children with special health care needs (CSHCN). Within each of Puerto Rico's health regions, a Regional Medical Director is responsible for the implementation and supervision of the different programs. At the regional level, the MCH program has MCH Regional Directors and Coordinators. This staff is under the supervision of the Regional Medical Director administratively and to the state level in the normative function. CSHCN services are provided through seven pediatric centers or satellite units, one rehabilitative hospital, the specialty clinics at the University Hospital, and 7 immunology centers for AIDS patients. The administration of Title V allotments as well as other federal programs is supported by several of the components of the Department of Health. Among these it is important to highlight the role of the Budget Office, Office of Federal Affairs and the Secretariat for Auxiliary Services.

1.5.1.2 Program Capacity

Historically, Puerto Rico's MCH program has played many different roles in serving mothers and children, including providing direct services, administering population-based programs, and assuming responsibility for core public health functions.

Before the Reform, the MCH program provided preventive primary care services for pregnant women, mothers and infants, and preventive and primary care services for children. These services were provided through a network of clinics located at DTC/FHC across the Island. However, as mentioned elsewhere, these services have been delegated to the network of primary providers of the health insurers.

The role of the MCH program has been refocused to the core functions of public health such as needs assessment, policy development and assurance. In addition, we also complement services not covered by the Government Insurance Plan and have developed new programs such as Home Visiting for at risk pregnant women and children under three and an infant seat leasing program in four regional hospitals.

During FY 1999-2000, the implementation of a Universal Alcohol Demonstration Screening Program was initiated in the west regions of Aguadilla and Mayagüez with the partnership of Triple C. During FY 1998-1999, the MCH Program was responsible of providing services in three municipalities out of the Health Care Reform (San Juan, Carolina, Trujillo Alto).

As described above, Puerto Rico's MCH program plays many different roles in serving mothers and children, including directly providing services, administering population-based programs, and assuming responsibility for core public health functions. Unlike many states' MCH programs, Puerto Rico had assumed lead responsibility for providing primary care services to all its low-income citizens. A

detailed discussion of the range of services provided by the MCH Division is presented below:

* ***Personal health services.*** Through PRDH's network of local public health clinics and hospitals and its contracts with other providers, an array of personal health services were provided to women, infants, children, and adolescents including CSHCN. Services that are provided to the MCH population include family planning, prenatal and postpartum care, high risk delivery, routine and intensive newborn care, child and adolescent health services (including the provision of Early Periodic Screening, Diagnostic, and Treatment {EPSDT} services), Comprehensive Adolescent Health program (CAHP), health education, nutrition counseling, and services provided under Puerto Rico's Special Supplemental Food Program for Women, Infants, and Children (WIC). Most of these services have been delegated to the health insurance companies and their provider network.

PRDH also provides the MCH population with access to school health, oral health, and mental health services. Under its school health program, the Department of Education contracts with other providers to complement ophthalmology, optometry, ENT, psychology, and audiology services to eligible Title I and special education children. The oral health services are very well covered through the GIP. Pregnant women with substance abuse problems receive care from primary providers in coordination with PRDH's Administration of Mental Health and Anti-Addiction Services and other private providers.

* ***Services to CSHCN.*** The CSHCN program provides services to eligible chronically ill and disabled children through its seven pediatric centers, one rehabilitative hospital, specialty clinics at the University Hospital, and 7 immunology centers for AIDS patients. At these facilities, eligible children receive specialty care, rehabilitative and ancillary services, assistive technology services and devices, AIDS related services, services for hemophiliacs, children with other genetic and metabolic disorders, and mental retardation. The CSHCN program also provides care coordination services to special needs children; however, the service focuses primarily on children with developmental disabilities between the ages zero and three who are eligible for Puerto Rico's Early Intervention program. The CSHCN program has provided training to staff graduate nurses of the Pediatric Centers in a service coordination model. Other nursing personnel relocated at the Centers as a result of privatization of health facilities due to the health reform have also been trained in care coordination for CSHCN. These personnel will work in collaboration with the Home Visiting nurses and case management staff of the insurance companies under HCR to assure a comprehensive delivery of services. Through the GIP, CSHCN access primary, secondary and tertiary

services. The Pediatric Centers are providers of specialized services. Title V funds complement services not covered by the HCR. Insurance companies are billed for services rendered at the Pediatric Centers and reimbursement monies revert to the Pediatric Centers. The Association of Parents of Children with Disabilities (APNI, Spanish acronym), in coordination with SSDI, assists the program to develop parents' committees in each health region in order to identify unmet needs of families and children and local resources in the communities to satisfy other needs.

* ***Population-based services.*** The Puerto Rico Department of Health administers a variety of population-based programs, including a newborn metabolic/genetic screening program, an immunization program, a prenatal care outreach program with access to a toll-free information line, a service directory co-sponsored by SSDI and MCH program, a folic acid campaign to reduce neural tube defects, HIV counseling and testing to prenatal patients and AZT administration to HIV positive patients on a voluntary basis. A task force has been appointed to initiate the needs assessment and the planning process for the implementation of the newborn hearing program.

* ***Public health functions.*** In addition to providing direct services to the MCH population, several divisions within PRDH are also responsible for conducting similar core public health functions for different segments of the population, including needs assessment, assurance, and policy development. For example, the MCH program within the PRDH conducts population-based needs assessment for MCH populations and develop standards of care for services provided under their programs. The Department of Health is responsible for developing guidelines for the providers of the HCR. The prenatal care and pediatric manuals were updated in 1999. The home visiting manual will be updated during the current year, taking into consideration the findings of an evaluation of the Home Visiting Program performed during the first trimester of the year 2000.

Another important achievement on this area was the development and approval by the Secretary of Health of a public policy aimed at improving the sexual and reproductive health of our population. This policy is a very comprehensive one that includes genders, family planning services, STD's including HIV/AIDS, and adolescents. During FY 2000-01, the MCH program will continue the dissemination and discussion of this public policy with concerned professionals, programs and organizations.

The CSHCN program, in collaboration with Medicaid, has established a process for the identification of the special population throughout the Island. Data include the population being served at the Pediatric Centers and the new patients identified by the primary providers of the GIP. Additionally, the Medicaid MA-2 form (the intake form) was revised by a team comprised by the CSHCN director and evaluator, the

MCH Epidemiologist, Medicaid staff, ASES representatives and ODSI. This information is a useful tool in the development of an effective and efficient managed care model of service delivery. This activity will be described in more detail in the Annual Report.

1.5.1.3 Other Capacity

The PR MCH program has 35 full time positions, nine more than last year (Table 3).

The MCH director is a board-certified pediatrician who holds a master degree in public health. He has occupied different positions at the Puerto Rico Department of Health for 26 years. He has been a primary health care provider, director of a pediatric residency program, director of the MCH program at regional level and holds the present position since December 1990. He was honored as the best student graduated from the MCH program at the 25th anniversary of the School of Public Health.

The deputy director is a BSN who also holds an MPH. She has been a staff member of the state MCH program for the last 16 years.

The MCH Epidemiologist holds a master's in science in epidemiology and, a DrPH Candidacy from the University of Michigan. He has been charged with the responsibility of improving the data capacity of the MCH Division and developing the Title V Evaluation and Informatics Section.

In addition to the central staff already described, there are eight out stationed teams located at regional level. These are comprised of an average of 5 positions: 1 MCH director, 1 coordinator for component A, 1 coordinator for component B, 1 coordinator of adolescent health services, 1 perinatal nurse and one health educator in some of the regions.

At local level, the personnel consists of one or more home visiting nurses and health services coordinators (outreach workers). As of June 2000, there were 103 home visiting nurses and 85 outreach workers across the Island. In **Appendix 6** the reader of this application may find a description of the tasks performed by home visiting nurses, perinatal nurses and outreachers.

TABLE NUMBER 3
SUMMARY OF THE MCH PROGRAM STAFF

Position/No. Of Staff	Qualifications	Main Responsibilities
1 MCH Director	Board Certified Pediatrician, MPH	Oversees the MCHP, SSDI, Healthy Start Program
1 MCH Sub-Director	BSN, MPH	Oversees all the administrative components of the MCH program.
6 Regional Coordinators	5 RN'S, 1 BA	Assure follow-up to the implementation of the MCH work plan at assigned health regions.
1 OB/GYN Consultant	MD	Provides technical assistance on reproductive health.
1 Nutritionist	MPH	Consultation on nutritional education for MCH population.
1 Evaluator	MS	Supports Healthy Start Project
1 SSDI Coordinator	BHE, MS	Coordinates SSDI work plan.
4 Health Educators	2 BS, 2 MPHE	One provides support to the adolescent health program and three to Healthy Start, Alcohol Screening and SSDI.
2 Social Workers	BA	Provide social work support to the comprehensive adolescent health program.
1 Psychologist	PhD	Support in psychology to the comprehensive adolescent health program.
1 Adolescent Health Director	Pediatrician with MPH	Directs the comprehensive adolescent health program.
1 Adolescent Health Coordinator	BSN	Supports the comprehensive adolescent health programs.
1 Epidemiologist	MSc., DrPH Candidate	Analysis and evaluation of MCH data, epidemiologic studies.
1 Assistant to the Epidemiologist	Office Clerk	Assists the epidemiologist and other Division needs.
1 Abstinence Education Coordinator	Pediatrician, MPH, MS	Coordinates abstinence education activities.
1 Coordinator Healthy Start Program	Pediatrician, MPH	Coordinates Healthy Start work plan.
1 Accountant	BA	Fiscal officer
7 Secretaries 1 Office Clerk		Support all staff.
1 Pediatric Consultant	Pediatrician	Consultant on pediatric and adolescent health issues and injury prevention coordinator.

TABLE NUMBER 4
SUMMARY OF CSHCN PROGRAM STAFF

Position/No. of Staff	Qualifications	Main Responsibilities
1 CSHCN Director	Pediatrician, MPH	Oversees the CSHCN and Early Intervention (Part C) programs
1 Consultant services to CSHCN	MD, MPH	Support to the CSHCN director in service and management issues.
1 Fiscal Affairs Coordinator	MBA	Supervise accountant and fiscal auxiliary and support in all of the Division fiscal affairs.
1 Accountant	BA	Intervention of documents and procedures to “account payable” and “account balances”.
2 Executive Functionary	BS	One receives data reports, prepares yearly statistics and collaborates in the coordination of data systems. Another is responsible for human resources issues.
1 Health Educator	BS	Coordinates all public awareness and educational activities for public and private providers and the community in general.
1 Evaluator	BA, MPH	Evaluation and monitoring of services to assure compliance with the law and bureau objectives.
1 Legal Advisor	JD	Offers legal advise to the CSHCN director, staff and collaborators.
1 Quality, Practices and Services Advisor	MA, ABD	Develop requests for funds; implement the medical home concept and community outreach.
1 Secretary	Associate Degree in Secretarial Sciences	Secretarial duties for the program
1 Data Entry	Associate Degree	Data entry to the information system and other clerical duties.
1 Office Clerk	HS	Clerical duties for the program
1 Folic Acid Campaign Coordinator	MD	Coordinate activities to comply with the folic acid campaign to prevent NTD’s.
1 CDC Fellow	RN, MPH	Assist the folic acid campaign coordinator, data collection and management, monthly reports, data analysis.

The CSHCN program has fifteen (15) positions at the central level (see Table 4). The CSHCN director is a pediatrician dedicated to private practice during 19 years; with an MPH degree with outstanding achievement. She holds the responsibility for the implementation of the Early Intervention Program in PR. The consultant of the division of CSHCN has an MPH in Health Policy and Management.

The operational level consists of 7 Pediatric Centers with a team of physicians, nurses, social workers, nutritionists, allied health professionals, secretaries, office clerks, medical records technicians, administrators, accountants, fiscal assistants, data entry and other support staff. The Division of Habilitative Services has integrated the services of an Administrator of Information System, an important component in order to obtain reliable data and establishing linkages with existing data banks related to the special population in PR. It is important to highlight that with the implementation of the HCR the administrative branch of the Department of Health (AFASS) was eliminated. As a consequence, the categorical programs have to assume AFASS role and provide for the program management at central and regional levels.

Financing of the support structure and services at the Pediatric Centers is given by state and other non-Title V funds. During 1998-99 we had a total of one hundred and ten (110) FTE's available to the seven Pediatric Centers to supplement and balance the centers needs and the Title V resources. Other direct services staff is also available to serve the Title V population at the seven Pediatric Centers. One hundred and seventy-one (171) direct services FTE's are paid by funds other than Title V.

1.5.2 State Agency Coordination

The needs of the MCH population are multiple and complex. Because of this, there is no public or private agency, program, or community based organization that can satisfy all the needs of the most vulnerable population comprised of women in their reproductive age, children and adolescents. It is therefore imperative to establish appropriate coordination mechanisms among all concerned entities in order to reduce duplication and fragmentation of services and to be more efficient in the utilization of the scarce resources available.

In Puerto Rico, we have in place fairly satisfactory coordination mechanisms among several public agencies and other sectors of the community at the state, regional and local levels. These coordination mechanisms are at both formal and informal levels. The Department of Health has established formal relationships with other state public agencies, local public health agencies, academic institutions, federally qualified health centers and tertiary health care facilities. All of these formal arrangements enhance the capacity of the MCH/CSHCN programs.

This formal coordination is the outgrowth of established laws and executive orders of the Governor, which mandate specific agencies and programs to sit at the table to coordinate certain types of services for the MCH population. There are also memorandums of understanding (MOU) among agencies and programs, which enhance the coordination of

services. Other formal mechanisms, which contribute to the achievement of this goal, are interagency committees, task forces and coalitions, among others. Several of the laws, executive and administrative orders and committees require the participation of consumers.

At this point, we want to highlight some of the laws, executive orders, MOU and committees that enhance coordination among all concerned entities, which serve the MCH population. The central staff of the MCH/CSHCN programs are regular members of most of these arrangements.

- Law No. 27 – Enacted in July 1992, allows health care professionals to provide prenatal care and postpartum services to minors without parental or guardian consents.
- Law No. 51- This law was enacted on June 7, 1996. It mandates the provision of comprehensive educational services to individuals up to 21 years of age who have special educational needs. The law requires the establishment of Advisory Council. An outstanding responsibility of the Department of Health under this law is to screen all children born in PR in facilities of the DOH or privatized, for developmental delay during the first three months of age. Identified children will be referred to the Early Intervention Program (EIP) with parental consent for eligibility determination and for provision of services until age 3 years. This strategy will assist the program to increase the number of children identified and enrolled during the first year of age. From ages 3 to 21, the Department of Education is ultimately responsible for providing educational and related services and the required coordination with six other agencies.
- P.L.105-17 - Infants and Toddlers with disabilities (Part C of IDEA). On April 8, 1992, the Governor of PR signed Executive Order No. 1992-28 amending Executive Order No. 5427-A of August 14, 1989 to comply with PL. 102-119, Inter Agency Coordinating Council (ICC) requirements.
- The ICC has been organized into committees to deal with identified areas of concern in the system: Members are actively involved in transition from Part C to Part B services, developing a central directory and plans for training child care providers with concerned agencies.
- Law No. 70 - Enacted in August 1997. It mandates the Secretary of Health to establish a committee charged with the responsibility to develop studies and provide recommendations for the reduction of infant mortality. The law requires an interagency committee including ASES, comprised of nine members under the leadership of the MCH Director.
- Executive Order No. OE-1997-13 - Our Children First (“Nuestros Niños Primero”) under the leadership of the First Lady gathers 21 agencies and six representatives of the community.
- Executive Order No. OE-1997-12 - Timely Rescue (“Rescate a Tiempo”) comprised of 12 agencies. The goal is to prevent school desertion.
- Healthy Start Consortium and Advisory Board to the MCH programs. Currently, it is comprised of about 40 members who represent public agencies including the Department of Health, academic, community based organizations, Medicaid, ASES, WIC, consumers, etc.
- State SSDI Committee and eight Regional Working Groups - Integrated by several agencies and consumers.

- Adolescent Task Force - Includes Mental Health, Department of Education, Community groups.
- Interagency Network for the Prevention of Child Abuse and Neglect - Includes the Department of Justice, Police, Department of Education, Department of Health (mainly MCH staff) and others.
- Advisory Board of the Department of Family - Includes several agencies and community organization.
- Advisory Board of the Midwife Training Program of the School of Public Health - The MCH Director is an active member.
- Committee of the University Affiliated Program (UAP) - Includes consumers.
- Committee for the Promotion of Folic Acid Campaign - includes the Department of Education & Puerto Rico's chapter of March of Dimes.
- PR Safe Kids Coalition - Includes private enterprises, the Police Department, Fire Department and many community agencies and individuals.
- Administrative Order No. 95 - The Metropolitan Pediatric Center is integrated to the University Pediatric Hospital to maximize its administrative functions and to better serve the special needs population. Normatively, the Pediatric Center responds to the Division of Habilitative Services.
- Advisory Council of Special Education to the Secretary of Education - The CSHCN director represents DOH.
- State Council on Developmental Disabilities - The CSHCN director represents the Secretary of Health.
- United Funds of PR - CSHCN director participates with other representatives of the community.
- Administrative Order 129 – To establish regulations for training in breastfeeding through continuing education for all health professionals.
- Law 32 – Enacted in January 10, 1999. To establish areas designed for breastfeeding and change diapers for young children in malls, government centers, ports and airports.
- Administrative Memorandum No. 09-1993 - Which allows two hours to take children for vaccination.

At the regional level the MCH staff participates in the following committees:

- Regional Network for Child Abuse & Neglect, includes MCH Staff.
- Regional SSDI working groups integrated by many programs, which serve the MCH population. These include consumers.

At local levels, the coordination is more informal, but supported by state laws and MOU's. Among the MOU we can mention the following:

- Medicaid, WIC and MCH
- SSDI Regional Working Groups (RWGs)

- Regional Interagency Networks for the Prevention of Child Abuse and Neglect
- Department of Education for Early Intervention system including transition procedures
- The Early Intervention Program collaborating with Our Children's First Initiative for the identification and referral of children with developmental delays.

There are also systems in place for the coordination of perinatal services. The Healthy Start Project developed a tracking system towards this goal. Through the Visiting Nurses program the high-risk infants from birth to 3 years of age are identified and referred for evaluation to EIP.

II. REQUIREMENTS FOR THE ANNUAL REPORT [Sec. 506]

In the following pages you will find a description of the activities carried out during the reporting period towards the achievement of national and state performance measures, information regarding the use of funds and the extent to which funds were expended consistent with the application submitted for FY 1998-99.

2.1 Annual Expenditures

Please refer to required budget Forms 3, 4 and 5. Most of the Title V funds are used to support salaries and fringe benefits of staff that perform tasks at the different service levels of the pyramid, to purchase contraceptive methods, to pay mileage for home visiting nurses and outreachers, for educational materials, professional development to support the interactive information line, to support the distance learning program and administration among others.

2.2 Annual Number of Individuals Served

Forms 6, 7, 8 and 9 provide the information required.

2.3 State Summary Profile

Form 10 summarizes the PR Block Grant Services Profile.

2.4 Progress on Annual Performance Measures

A. Please refer to annual performance indicators row on Form 11.

B. Accomplishment by levels of the MCH's pyramid.

Figure 10 depicts some of the initiatives, services and programs that in one way or another contribute to pursuing the goal of improving the health and well being of the MCH population in the Island. These initiatives, services and programs are supported not only with Title V funds, but also with state, other federal resources as well as local funds.

During the reporting period, 1998-99, the following accomplishments could be identified by levels of the pyramid:

Direct Medical Care

a. Pregnant women, mothers and infants.

As discussed through the overview, the primary preventive services for pregnant women, mothers and infants are covered through the GIP in areas of the Reform. Seventy-five municipalities out of 78 were under the Reform during the reporting period. In order to facilitate access to prenatal care, routine infant care and immunizations, no co-payment is permitted for the provision of these services. By December 1999, 368,659 WCBA (15-44 years) and infants had the GIP. In the municipalities of San Juan, Carolina and Trujillo Alto, services were provided in the traditional manner with support of Title V funds. During the reporting period, the MCH program served 15,697 pregnant women, 41,843

family planning, 1,262 postpartum women, and 10,947 infants with personnel paid with Title V funds.

Regarding immunization coverage of children under two years of age, we have had a great success. In 1992, the coverage was only 38.4%, compared to 93.7% in 2000. This achievement has been a joint effort of many partners including, but not limited to the immunization program, the MCH/CSHCN and WIC programs, federally funded projects (329/330), several public agencies, community organizations as well as the private sector.

The pediatric AIDS and MCH programs in Puerto Rico have worked together to assure prenatal counseling, testing and treatment with AZT on a voluntary basis to all HIV positive pregnant women. Puerto Rico has been able to obtain consent for HIV screening from as many as 86% of pregnant women (1996). In 1999, 83 women were found positive for HIV testing; all of them were treated according to the established protocol. Puerto Rico has been successful in reducing the perinatal transmission, from 48 cases reported in 1992 to only one case pediatric AIDS diagnosed in 1999. Our program has been thoroughly evaluated by federal entities and recognized as an excellent one. The pediatric AIDS program operates with a mix of state and federal funds.

The neonatal screening program for hereditary diseases: This program is supported with $200,000 earmarked by the Legislature. During calendar year 1999, it served 57,044 out of 59,685 live births. This figure represented 95.6% of all live born during the calendar year. Thirty-seven (37) cases were diagnosed for the four conditions screened for in Puerto Rico: PKU- 6 cases; Hypothyroidism - 12 cases and Sickle Cell Anemia-19 cases. No cases of Galactosemia were identified. All these patients were properly managed.

Postpartum education: Title V funds are used to pay for salaries of 8 perinatal nurses stationed at area and regional hospitals. These nurses are key for the provision of postpartum education on an individual or group basis, making referrals to primary services, disseminating educational materials and collecting information.

During the reporting period the perinatal nurses conducted orientation and education sessions for postpartum women covering a wide array of topics such as: the importance of the postpartum visit and family planning, breastfeeding, newborn care and proper sleeping position, need of pediatric care, the importance of the use of the infant car seat, etc. During FY 1998-99 the perinatal nurses provided 8,513 individual orientations and group sessions to 7,158 participants.

b. Children

As of December 1999, a total of 641,695 children and adolescents, including CSHCN (1-19 years old) benefited of the GIP. These children had access to needed primary and preventive services through the primary provider selected by their family. On the other hand, the MCH program served a total of 22,928 children and adolescents in the remaining four municipalities out of the HCR. During FY 1999-00, the Head Start program provided

comprehensive pediatric services through coordination with the primary providers for over 37,246 pre school children; of these, 5,162 (13.9%) were CSHCN.

c. CSHCN

During the FY 1998-99 a total of 10,027 children 0 to 21 years of age received services at the Pediatric Centers. This number represents 14% of the estimated 0-19 years population for 1998 (1,292,226) using a very conservative approach (5.5%) for the estimated percentage of CSHCN population (71,072).

Services included specialized services, orthoses, prostheses, hearing devices, eyeglasses and assistive technology equipment. Of the total of children served, 4,420 representing a 44%, were new admissions. A total of 127,245 services were delivered, including:

Medical Services	39,077 (30.3%)
Oral Services *	1,390 (1.16%)
Allied Professions Services	88,168 (68.5%)

*Services rendered by Pediatric Centers at Caguas and Ponce.

As we have mentioned before, the total of children served has decrease for the past three years. For the total number of children served there has been an increase in the number of new patients. This may be as a result of the public awareness efforts of the Pediatric Centers and the coordination established with the insurance companies.

In terms of the total of visits rendered there has been an increase of 9% since 1996, the highest figures account for related services followed by medical services (**Figure 11**). Physical therapy was the most frequent service provided followed by occupational therapy and speech and language therapies.

It is important to underline that the Pediatric Centers offer a unique structure for CSHCN in PR where medical, related services, support, emotional and socio-economic needs are addressed following a comprehensive, family centered approach. This constitutes a strength to add on the collaboration established with the GIP providers.

During the past two years the Genetic Program directed by Dr. Alberto Santiago Cornier has evaluated five hundred and eighty-three (583) new patients. The most common diagnoses are chromosomal and metabolic disorders. Genetic counseling, nutrition and nursing services were provided to two hundred and fourteen (214) new patients. The number of clinics has increased from two hundred and two (202) in 1998 to four hundred and twenty-nine (429) in 1999 for a 53% increase. The vast majority of the newly diagnosed cases continue follow up at the regional clinics lessening the burden of transportation to the Metropolitan Area. All the genetic clinics are located within the Pediatric Centers, facilitating access for children and families and with the benefit of sharing the multidisciplinary staff available at the Pediatric Centers. Genetic services at the Metropolitan area continue to be provided . Most common diagnoses are histidemia, organic aciduria, and non-ketotic hyperglicenemia.

Enabling Services

a. Pregnant women, mothers and infants.

The implementation of the Health Care Reform in Puerto Rico has made possible that the MCH program could develop other programs and services in addition to complementing direct care. One of these new programs is the Home Visiting Program. The target population of the Home Visiting Program are pregnant women and children under three years of age with health and social risk factors. During the reporting period, the 103 Home Visiting Nurses served 15,531 patients and their families. These included pregnant women, children, postpartum women and other clients. The Home Visiting Nurses have been able to provide or coordinate a wide array of services for participating families. The work of the Home Visiting Nurses is supported by the community health workers or outreachers. The total number of home visits generated during the reporting period was 31,093.

It is important to highlight that during the reporting year we were struck by hurricane Georges. Due to the emergency the local staff; home visiting nurses and health coordinators had to be assigned to centers of refugees for several months. Their role there was to assess the needs of the refugees, provide treatment to those in needs, provide orientation on different topics, to support and coordinate health and other human services as needed. Therefore, direct services were provided to thousands of refugees among different age groups.

Outreach activities are carried out by community health services coordinators who are totally funded with Title V. Currently, there are 85 outreachers who are based at the municipality level and work in coordination with Home Visiting Nurses. Their tasks include case finding, health promotion, patient education, family orientation in accessing and maintaining continuity of care through the primary providers selected by the family, identification and reporting to concerned individuals of any system barriers or issues affecting the MCH population, and coordinating services among community entities. Several of the outreachers have been trained on the curriculum of March of Dimes "Comenzando Bien" and they are implementing it at their local communities.

The postpartum education was briefly discussed in the previous section. Case management services are provided for HIV positive pregnant women and infants by the Pediatric AIDS staff in collaboration with the Home Visiting Nurses.

During FY 1998-99 the WIC program served an average of 40,236 pregnant and postpartum women, 48,528 infants and 202,675 children. There is a Memorandum of Understanding (MOU) between both programs for the inter-referral of cases.

As required by law, the PR MCH program operates an Islandwide toll free line (1-877-641-2004) aimed at providing information about the availability of health care and other human services provided through other public and private entities. During the reporting period, a total of 15,798 services were requested, compared to only 1,610 last year. This increase is the result of the implementation of the new toll-free line available 24 hours a day and seven

days a week. In addition, the Toll Free Line has been widely announced through TV and printed media. It allows parents and inquirers to receive general information of services for CSHCN and has the capacity to transfer calls directly to the Pediatric Centers for detailed information.

The most common requests of information through the Toll-Free Line during the reporting period were: 1) adolescents who wanted information on how to address their pregnancy with their parent or guardian; 2) adolescents who requested information regarding availability of pregnancy termination options; 3) adolescents who need information about paternity test; 4) information regarding contraception; 5) information about breastfeeding; 6) whether the GIP covers prenatal care for adolescents; 7) whether the GIP covers services for LBW infants; 8) information related to sexual relations and other general topics.

It is important to highlight that there are other toll-free lines, which address other maternal, and child health issues in Puerto Rico. These include:

- The APNI ("Asociación Pro-Bienestar de Niños de Puerto Rico") or Parents of Special Health Care Needs Children Association Toll free line: 1-800-981-8393.

- ASES Hot Line: 1-800-981-2737

- The Child Abuse and Neglect Hotline - used to report suspected cases of child abuse and neglect: 1-800-981-8333.

- Rape Victim Crisis Center: (787) 765-2285

- Puerto Rico Lacta Toll Free Line: 1-877-PR LACTA (775-2282) (breastfeeding information)

b. Children

The enabling services previously described also apply for this segment of the MCH population.

c. CSHCN

A Memorandum of Understanding (MOU) between the Shriners Hospitals, the Title V, the CSHCN Program and the Puerto Rico Department of Health has been completed to facilitate that families and children who decide to travel to the mainland for orthopedic surgeries are oriented about the services available in Puerto Rico by our staff at the Pediatric Centers prior to traveling. The coordination of needed services with the primary physicians under HCR when returning to Puerto Rico is facilitated by the Pediatric Centers.

A cadre of registered nurses with knowledge of the special population has been selected and trained in service coordination skills. A working plan has been developed by a team

including nurses and other collaborators from the Pediatric Centers, addressing some of the identified needs by each regional group.

The insurance companies under the HCR provide support to families through the Care Coordinator for CSHCN identified at each of their central offices, in coordination with the medical director at each Pediatric Center. ASES also provides a forum for filing complains at PROBENE, which identifies families' concerns and addresses the primary physician looking for prompt solutions. SSDI Regional Working Groups have been actively collaborating in helping families to move around the system.

The Asthma Program (Coalition Against Asthma) has identified various needs of this population within the managed care setting under the HCR. Meetings with Triple C have resulted in new provisions that will increase access to specialized services and to medications according to the standards of care. Education to primary physicians aimed at changing behaviors and attitudes is provided, expecting a gradual increase in the number of referrals of the more severe cases to our specialized centers. Indicators of morbidity expected to improve given the asthma managed care are the use of short action medications, decrease in the number of emergency room visits and in hospitalizations.

During fiscal year 1998-99, a total of 57 children and adolescents (3 months-21 years old) were supported by the Catastrophic Illness Program Fund under the Division for Habilitative Services. They were granted with amounts ranging from $500.00 to $225,000.00 per patient. Patients with biliary atresia and leukemia received the higher amounts. The table that follows summarizes the amount of money provided by number of patients assisted. A total of $3,008,919.00 of state funds was used to support these 57 patients; showing an increase of $882,223 expended funds, as compared to 1997-98. Most of them were treated in the mainland.

TABLE 5
CATASTROPHIC ILLNESS PROGRAM FUND
1998-99

AMOUNT	NUMBER OF PATIENTS
< $1,000	2
$1,001 – $10,000	13
$10,001 - $20,000	7
$20,001 - $30,000	11
$30,001 - $50,000	5
$50,001 - $100,000	8
$100,001 - $200,000	7
+ $200,001	4
TOTAL = $3,008,919	**57**

Population Based Services

a. Pregnant women, mothers and infants

Form 6 summarizes the newborn screening activity and its results. Law No. 84, enacted in 1987 mandates that every infant born alive in Puerto Rico must be screened for PKU, Hypothyroidism and Sickle Cell Anemia. In 1999, 95.6% of all live born infants were properly screened and the 37 diagnosed cases received adequate treatment, counseling and follow up by the staff of the Hereditary Diseases Program. A total of 57,044 patients were screened for galactosemia (95.6%), but no cases tested positive for this inborn error of metabolism. Children positive for metabolic disturbances are referred to the Pediatric Centers for evaluation and follow up by the Nutritionist; special formulas if recommended by the specialists are provided for those over five (5) years of age.

Law 25 of 1983, mandates immunization of all children according to the latest immunization schedules. In 2000, we accomplished 93.7% immunization coverage among children through 2 years of age. Our performance objective for Year 2000 is 90%.

After the initiation of the HCR, the MCH program has enhanced its public education activities in the community. These activities are conducted by the MCH staff at all levels of the system (central, regional and local). Many health issues are addressed through

conferences, orientations, health fairs, radio programs, TV participation, dissemination of education materials, posters and the interactive educational program.

During the reporting period we documented over 6,424 educational and outreach activities across the Island reaching 138,605 individuals. These activities were provided in schools, public health facilities, private offices of health care providers, churches and public housing projects among others. The MCH staff participated in 250 health fairs, documenting 36,325 participants. In addition, over 39 presentations were made in radio stations and 21 in TV channels that provided free time to convey health promotion messages. A Public Service Announcement promoting early prenatal care was aired for 7 weeks through radio, TV and newspapers supported with Healthy Start funds.

During the reporting period the MCH program, in partnership with the "Our Children First" program led by the First Lady, the Puerto Rico Safe Kids Coalition and the Traffic Security Commission were very active conducting activities aimed at preventing the 10 most common unintentional injuries. Activities included press conferences, dissemination of educational materials, radio programs and community education in general. In addition, to disseminating thousands of leaflets which contain a family checklist for the 10 most common injuries in children our staff participated in activities aimed at checking the appropriate use of the infant seat.

b. Children

Most of the activities described above also impact the population 1-21 years of age including children with special health care needs.

c. CSHCN

An area of impact for CSHCN population based services is the NTD's campaign. Data collected through the Birth Defect Registry during this year revealed an incidence of 0.89/1,000 live births. This rate represents half the incidence reported at the beginning of the folic acid campaign in 1994 (1.6/1,000 live births). This decrease may be attributed to the intense mass media campaign that took place last year in Puerto Rico including TV, movie theaters and messages in boxes of Kellogg's cereals and rice packs. Eight hundred (800) trainers reached 75,000 students of junior and high school levels. An instructional module was prepared to guide the Department of Education to perform curricular changes so that our students receive appropriate information regarding folic acid inclusion in their daily diet to prevent NTD.

Another activity is this area of the pyramid is the initiation of a door-to-door orientation to physicians regarding their responsibilities under Educational Law #51 to identify children with disabilities or developmental delays at birth or before three months of age and referral to the early intervention system. It started in the Fajardo Region, followed by Caguas and Arecibo. An orientation package was prepared with a pre and post test with continuing education credits. This initiative is expected to result in a higher number of referrals to the

Early Intervention Program since doctors are advised that the program is free of charge for families and that referrals doesn't affect their capitation.

Infrastructure Building Services

Figure 10 depicts Puerto Rico's MCH pyramid. At its base are listed some of the infrastructure building services that support needs assessment, policy development and assurance for quality of services according to current standards of care for the three groups encompassing the MCH population.

Both the MCH/CSHCN programs have the minimal staff at central and regional levels (Tables 3 & 4) to carry out the required needs assessments to develop the appropriate plans to address the identified health needs; to develop and promote policy and legislation in benefit of the MCH population; to update and disseminate guidelines for the delivery of primary care services; to evaluate the quality of care provided through a diversity of activities such as chart audits, self administered questionnaires, etc. These functions are carried out with the support of many partners, which include programs which provide specialized services to some of the sub-groups of the MCH population (WIC, Medicaid, Head Start program, PROFAMILIA, LACTA Project); coalitions, boards, interagency committees, Memorandums of Agreement, among other components.

The MCH/CSHCN staff carried out over 300 meetings with different partners, such as the Department of Education and the Family, Head Start programs, ASES, health insurance carriers, coalitions, community based organizations and many others. These meetings were very helpful in the coordination of services, for discussion of MCH issues, to provide orientation regarding the Health Care Reform, to provide technical assistance and to share information. Looking at the different components of the infrastructure building services for MCH/CSHCN programs we would say that with proper coordination, cooperation and collaboration most of the national and Puerto Rico negotiated performance measures are addressed by one or more of the programs, projects, committees, coalitions and boards listed in the pyramid. For example:

- The percent of Children with Special Health Care Needs (CSHCN) in the State who have a "medical/health home" PM#3.., the denominator of the equation is being addressed by the Title V program in coordination with Medicaid, ASES and the insurance companies. In contrast to other states, Puerto Rico was not included in the national survey that will gather information to be used for this indicator. Puerto Rico faces particular challenges to comply with the concept of medical home as presented, due to constrains related to the Medicaid cap and non-availability of SSI benefits for our special population.

- The percent of newborns screened for PKU, hypothyroidism… PM#4 is addressed by the MCH program and the Program of Hereditary Diseases housed at the University Pediatric Hospital.

- The percent of children through age 2 who have completed immunizations… PM#5 is addressed by the Immunization, MCH, WIC, Medicaid programs, the health insurance carriers as well as other public and private entities.

- The birth rate for teenagers… PM#6 is addressed by the MCH program, the Abstinence Education program implemented in partnership with Department of Education, the Department of the Family, community organizations and others.

- The rate of deaths to children caused by motor vehicle crashes… PM#8 is addressed with the support of the Traffic Safety Commission, the Safe Kids Coalition, the Puerto Rico Coalition to Reduce Teenage Drinking, the Police Department and many others.

- Percentage of mothers that breastfeed… PM#9 is addressed by the Committee to Promote Breastfeeding leaded by the MCH program, the WIC and Healthy Start programs, LACTA Project and the School of Public Health, among others.

- The percentage of newborns who have been screened for hearing impairment… PM#10 is addressed by a task force of physicians, audiologists, speech pathologists and Title V representatives. A technical assistance has been coordinated with Region II to support us in developing the program.

- The incidence of NTD… SPM#3 is addressed by the folic acid campaign and the interagency committee.

- The rate of deaths of children aged to 1 to 14 caused by Asthma… SPM#7 is addressed by a coalition of collaborators from the public and private sectors. A program has been established ("Los Colores del Asma") aimed at providing treatment and education to patients and families as well as to providers.

Another important component of the MCH infrastructure is professional development through continuing education and skills building of primary providers to properly serve a high risk population that have been delegated to their care. Many partners, such as the School of Medicine and School of Public Health, professional associations, health insurance companies, and others support this activity. Our staff participated in continuing education activities through the interactive distance learning program that provided 7 activities registering 1,373 participants. Some of the topics covered during the reporting period were effective HIV/STD prevention, immunization, home visiting and health promotion and back to sleep position, among others. During this period, the program was interrupted for about 6 months due to effects of Hurricane Georges.

The University Affiliated Program of the School of Public Health is in charge of the Comprehensive System for Personnel Development (CSPD) component of the Early Intervention Program. A committee composed of fifteen members representing agencies and

universities have elaborated a CSPD plan for the next 3 years. A need assessment of the E.I. providers of the Pediatric Centers has been completed. The Division has also provided training to our direct personnel including administrative aspects, managed care and updates in various disciplines of benefit to the population we serve.

The combined efforts between the MCH staff and the Secretariat of Planning, Evaluation, Statistics and Information Systems resulted in an increase in the number of computers, hardware, software and other peripherals to enhance the data capacity at the central and regional levels of the MCH/CSHCN programs. The changes are summarized in Table 6.

TABLE 6
TECHNOLOGICAL MCH/CSHCN DATA CAPACITY

	MCH		CSHCN	
	1999	**2000**	**1999**	**2000**
CENTRAL LEVEL				
Computers				
Pentium computers	9	12	6	6
Pentium Laptop computers	2	2	2	2
486 Personal computers	4	4	2	2
Multimedia				
PC with multimedia capabilities	4	11	All	8
Printers and Scanners and others				
Monochrome Laser Printers	4	4	1	1
Color Laser Printer	1	1	1	1
Color Desk Jets	3	3	5	6
132 Column Dot Matrix Printer	1	1	0	1
Scanners	0	1	1	1
Tape Backups Drives 120 MB	1	1	0	1
100 MB ZIP Drives	3	3	0	4
Infocus Projector	0	1	0	0
Security Cables for all computers	No	Yes	0	0
Software				
SPSS 9.0 for Windows	3	3	0	3
Windows 3.1 or DOS	0	0	0	0
Windows 95	15	15	5	5
Windows 98 Workstation	0	3	5	5
Microsoft Office Professional	15	18	All	All
Omnipage Pro 10	No	Yes	0	0
Agency Home Page address: http://wwwi.salud.gov.pr/	No	Yes	No	Yes
Internet access				
Network connection	15	17	All	8
Modem				
Multi-Modem Fax	1	1	1	2
REGIONAL LEVEL DATA CAPACITY				
Computers				
Pentium computers	8	8	7	30
Printers and Scanners				
Color Desk Jets	-	-	7	8
Scanners	0	1	7	6
Software				
Windows 3.11	-	-	7	30
Windows 95	8	8	-	12
Windows 95 NT Workstation	-	-	7	8
Microsoft Office Professional	8	8	7	30
Unisix System	-	-	7	7
Internet access				
Network connection	All	All	All	30
Modem				
Multi-Modem Fax	8	8	7	7

There is an ongoing effort to connect the MCH computers at the regional level to the main central network by modem. In this way, MCH regional personnel will be able to submit reports and

communicate more effectively with the central level.

The CSHCN Program hired a master level public health evaluator and a computer system analyst to help in the ongoing efforts of increasing the program analytic and programming data capacity. They are developing a database application with the main purpose of establishing an information system for patient record maintenance at the regional pediatric centers.

a. Pregnant women, mothers, infants, children and CSHCN

As stated in the overview, the available infrastructure needed to provide the direct care services for the population has been enhanced markedly. Besides federal statutes such as the Title V law, there are several local statutes, coalitions, boards and committees that also contribute to strengthen the infrastructure of the network of services for pregnant women, mothers, children, adolescents and children with special health care needs. These are briefly discussed in section 1.5.2.

b. CSHCN

During the reporting year significant activities have taken place at this level of the pyramid which will allow the program to improve services for CSHCN and families. In the midst of the various changes implemented by the HCR, the Pediatric Centers have remained as providers of specialized services for the special need population and their families. The Centers are located in the community where the children lives and provide orientation to families on the ways to access care along this complicated array of services.

Meeting with various stakeholders, providing continuing education to our staff and community providers, revisions of the established interagency agreements and a new agreement with the fifteen (15) Early Head Start consortiums along the island, are some of the activities geared towards better coordination of services, improving access and establishing linkages with parents and the communities.

The Division of Habilitative services in collaboration with the School of Allied Health Professionals of the School of Medicine of the UPR was involved in a study to compare test results among three devices to perform hearing newborn screenings before babies are discharged from nurseries in PR. This activity is part of the initiative in the planning stage for UNHS.

Thirty-two full term newborns participated in the study performed in the nursery within 48 hours of birth. Three screening devices were evaluated, the Natus Algo 2, an AABR, the Otodynamics Echo Check, and the Bio-logic AuDx, the last two are devices to perform otoacustic emissions. The majority of the newborns passed the AABR screening.

The next step of the UNHS in PR is the technical assistance with the purpose of looking to our system of services for children and designing a model that could be applied at hospital across the Island.

A Steering Committee was designated and already had their first meeting. Technical assistance requested to MCH will take place in August 22 to 24, 2000. The CSHCN Program has requested information from birthing hospitals in PR regarding if NHS is performed and the results. We are still receiving reply to the questionnaires.

Another area of collaboration with the School of Allied Health Professionals was the training of a group of professionals of various disciplines of the Pediatric Centers in the skills for the early identification, evaluation and treatment of toddlers suspected of having Autism. The group was trained by the Infantile Autism Program and during FY 2001 a pilot project will start in the Pediatric Centers at Metro Area and Ponce. This effort is geared towards earlier identification, proper orientation to families and provision of therapies using the TEACH method.

Significant outcomes of the various components of the infrastructure building services related to the performance measures include:

1) Changes implemented in the MA-2 form for the Medicaid Information System which will make it possible to identify the special need population and to gather information on medical conditions of the CSHCN. The MA-2 form is used for the yearly certification of our population for the GIP.
2) Collaboration with the PR Chapter of the Academy of Pediatrics facilitated initial approach to pediatricians for the introduction of the Medical Home concept and the Newborn Hearing Screening initiative.
3) In collaboration with the Immunization Program, CSHCN and siblings are receiving their immunizations at the Pediatric Centers; the service already started in Bayamón and Arecibo.
4) The significant decrease in the rate of NTD in PR was accomplished thanks to the intensive folic acid campaign using mass media, adolescent trainers and education of the DOE staff.
5) The planning phase of the newborn hearing screening program including a Senate bill for the enforcement of this initiative.
6) The Coalition of Asthma has already reached 100 families since August 1999 with outstanding results on evaluation studies including: decrease in hospitalizations and emergency room visits, better knowledge of the condition and improved quality of life, among many others.

In addition to the identification of the CSHCN in PR, Pediatric Centers are identifying needs of specialized services in the communities, contracting specialists and billing the insurance companies for reimbursement. The varied allied professionals available at the Pediatric Centers have also been certified as providers for the GIP. This is a definite strength for the Pediatric Centers since providers of related services under the GIP are scarce in relation to the demand for such services.

TABLE 7

C. Accomplishments of the National and State Performance Measures

Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Gather Not Available Data
	Yes	No			
1) The percent of State SSI beneficiaries less than 16 years old receiving rehabilitative services from the State Children with Special Health Care Needs (CSHCN) Program.		X	None.	Puerto Rico does not receive SSI allocation.	None, unless PR receives SSI allocation.
2) The degree to which the State Children with Special Health Care Needs (CSHCN) Program provides or pays for specialty and sub specialty services, including care coordination, not otherwise accessible or affordable to its clients.		X	-The GIP pays for medical and surgical subspecialty services, respiratory services, as well as for occupational and speech therapies in unlimited numbers. Physical therapies are provided upon recommendations of an orthopedic or a physical medicine specialist, up to 15 per year. Home health care is provided by the insurance companies who have identified a coordinator for the CSHCN at central offices.	-Home health care and respiratory services are being provided by GIP and by some major plans for severely compromised children, most of them with respiratory and GI conditions. -With the implementation of the Title V case coordinator it is expected that efforts with the insurance companies are strengthened.	-By September 2000, establish agreements between ASES, insurance companies and the PR DOH to increase access to services. -Establish appropriate indicators for the evaluation of the case coordinator program.

Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Gather Not Available Data
	Yes	No			
			-The Pediatric Centers provide nutritional services, eyeglasses, hearing devices, braces, orthoses, suction and urinary catheters with Title V funds. Early Intervention services are also provided at the Pediatric Centers. Care coordination training for nurses has been completed as well as Working Plan; will work in coordination with the special needs coordinator at the insurance companies. -Pediatric Centers continue to provide specialized and related services for CSHCN. Allied health professionals were certified as providers for the insurance companies.		

Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Gather Not Available Data
	Yes	No			
3) The percent of Children with Special Health Care Needs (CSHCN) in the State who have a 'medical /health home'.		X	-Train primary providers in the medical home concept; select the primary providers for Children with Special Health Care Needs. -The population of CSHCN is being identified for the past two years through combined efforts of Medicaid and ASES. -An instrument to assess provision of medical home will be prepared using the model provided by the AAP, to be used in a representative sample of the identified population.	-Continuous shifting in the provider networks threatens the continuity of care from birth to age 21. -Some data are now available related to the total number of CSHCN in the state. Further and continued efforts are needed. -Need of a common definition of what is CSHCN. This issue should be addressed by the MCHB. - PR was not included in the SLAITS Survey. We interpret this action as discrimination. -PR is not part of the National Hospital Discharge Survey.	-The MCHB should determine the tool to be used for the identification of the population. -Provide training on medical home in collaboration with AAP. -Develop and disseminate educational material aimed at families and primary physicians. -Improve our data collection system with support of the submitted proposals to MCH. -Link existing data banks related to CSHCN. -Continue advocating on behalf of PR to be included in national surveys planned in the future.

Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Gather Not Available Data
	Yes	No			
4) Percent of newborns in the State with at least one screening for each of PKU, Hypothyroidism, Galactosemia, Hemoglobinopathies (e.g., Sickle Cell diseases) (combined).	X		-Established law that mandates newborn screening for all live births. -Annual allocation funds of $200,000 from Legislature for the operation of the Hereditary Disease Program located at University Pediatric Hospital. -Excellent coordination between the Hereditary Diseases and the MCH programs.	None.	-To improve the tracking of doubtful cases.
5) Percent of children through age 2 who have completed immunizations for Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Hemophilus Influenza, Hepatitis B.	X		-Puerto Rico is the jurisdiction with the highest immunization coverage of children through age 2. In 2000, PR achieved 93.7% coverage. This achievement is the result of an excellent immunization program supported by the MCH program, the health insurance companies, private entities, etc.	-Family barriers; small proportion of families continue to see immunizations as a requirement for school enrollment but not as a need to protect their children's health. -Lost opportunities.	-Continue education to the general public and continued education aimed at primary providers.

Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Gather Not Available Data
	Yes	No			
6) The birth rate (per 1,000) for teenagers ages 15 through 17 years.		X	-The implementation of a comprehensive adolescent health program, which includes peer training as health promoters. -The implementation of an Islandwide Abstinence Only Education Program since August 1998, as a joint endeavor of the Departments of Health and Education. -The implementation of the Welfare Reform by the Department of the Family.	-Cultural barriers that impede sex education and the provision of family planning services to sexually active teens. -Percentage of sexually active teens. -Lack of legislation to allow health professionals to provide comprehensive primary and preventive services to teens without parental or guardian consent.	-To continue providing the abstinence only education program to at least 100,000 students in K-12 per year. -To continue lobbying for a bill aimed at passing a Law that allows health providers to render primary and preventive services to adolescents without parental consent. -Continue creating awareness among the public at large, health professionals and other entities which serve adolescents.
7) Percent of third grade children who have received protective sealants on at least one permanent molar tooth.		X	-Both Title V program and the Secretariat for Oral Health will continue promoting the use of this service, which is covered by the GIP.	-Lack of awareness regarding the need of this preventive service in the population at large. -Poor data collection mechanisms.	-Ongoing public education regarding the need of this preventive service. -By September 30, 2001, finish the mechanism aimed at collecting the data needed to monitor this performance measure. -To continue working with the Assistant Secretariat for Oral Health, ASES and the Insurance Commissioner to improve the collection of reliable data regarding this performance measure.

Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Gather Not Available Data
	Yes	No			
8) The rate of deaths of children ages 1-14 caused by motor vehicle crashes per 100,000 children.	X		-Partnership among many agencies and organizations promoting the use of seat belts and the infant seat. Some of these entities are: The Safety Traffic Commission, the Police Department, Safe Kids Coalition, etc. -An infant seat-leasing program across the Island.	-Driving under the effects of alcohol and other drugs. -Speeding. -Lack or improper use of the infant seats and seat belts.	-Ongoing enforcement of protective laws. -Ongoing public education.

Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Gather Not Available Data
	Yes	No			
9) Percentage of mothers who breast-feed their infants at hospital discharge.		X	- The Secretary of Health established a breastfeeding public policy in 1995. -An administrative order was established in 1998, which requires all health professionals to have at least 3 credits of continuing education on breastfeeding at the time of re-certification. -The MCH program leads a Steering Committee that has developed a 5-year plan aimed at attaining the year 2010 objectives related to breastfeeding. -There is much collaboration among several programs and entities which promote breast-feeding: the MCH program, the WIC program, the MCH program of the School of Public Health, LACTA Project, Sprint Telephone Company, PR Chapter of A.P.P, support groups.	-Hospital policies. -Negative attitudes of a significant number of women about this practice. -Lack of knowledge among health professionals and the public at large concerning the benefit of breastfeeding. -Lack of support to breastfeeding women in the workplace.	-Ongoing promotion of hospital policies, which facilitate breast-feeding practices. -Ongoing enforcement of the administrative order requiring continuing education credits on breastfeeding for re certification. -Ongoing public education. -Support for mothers through a toll free line inaugurated in May 1999. -A partnership between the Department of Health, LACTA Project and Sprint Telephone Company.

Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Gather Not Available Data
	Yes	No			
10) Percentage of newborns that have been screened for hearing impairment before hospital discharge.		X	-The MCH/CSHCN programs directors convened a working group to initiate the planning process for the development of a universal screening program. -Educate ASES and MCO on cost effectiveness of this prevention strategy. -A technical assistance has been coordinated for August 2000.	-This is not a standard service in Puerto Rico. -Lack of funds to routinely screen close to 60,000 live births per year. The estimated cost is around $900,000.00 per year to implement the program. -Capitation concerns of health insurance companies. - Proposals submitted to MCH approved but not funded.	-By September 30, 2001, promote the legislation aimed at including this service in the benefit package of all health insurance companies. -A bill was already supported at the Senate but it has not been approved yet. -Questionnaire sent to birthing hospitals requesting data on NHS.
11) Percent of CSHCN in the State CSHCN Program with a source of insurance for primary and specialty care.	X		-Because of the implementation of the HCR started in PR in February 1994, all children under 200% percent poverty line qualify for the GIP. In addition, those children who do not qualify for Medicaid will benefit due to the implementation of the CHIP program. -Pediatric Centers and Medicaid have collected data for this performance measure. -By July 1st, 2000, the HCR was implemented islandwide.	-Medicaid cap. -PR does not receive SSI funds.	-Ongoing outreach of the hard to reach populations with LPN recruited for this purpose. These LPN's are paid with CHIP funds. They are under the supervision of the Regional MCH Director. -Data from contracted billing company. -Modify encounter form to include health insurance data and update information system.

Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Gather Not Available Data
	Yes	No			
12) Percent of children without health insurance.	X		-The percentage of children without health insurance has dramatically decreased in PR due to the implementation of the HCR, which includes a GIP for all persons, under 200% poverty line. -By July 1st, 2000, the HCR was implemented Islandwide.	-Lack of sufficient state funds. -Medicaid cap. -Hard to reach populations.	-Ongoing outreach activities carried out by the MCH program and supported by Medicaid. -Request data regarding all children with a third party payer from Insurance Commissioner.
13) Percentage of potentially eligible children who have received a service paid by the Medicaid Program.		X	-The implementation of the HCR and decreasing the waiting time for certification in the Medicaid program. -Ongoing outreach activities.	-The high proportion of children under the poverty line (66%). -Medicaid cap -Hard to reach population.	-Ongoing outreach activities aimed at finding children under the poverty line without the GIP. -Referral to the Medicaid program for certification. -It is unfair to compare PR with the rest of the States due to the Medicaid cap.

Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Gather Not Available Data
	Yes	No			
14) The degree to which the State assures family participation in program and policy activities in the State CSHCN Program.		X	-Family-centered practices of early intervention have been established in Pediatric Centers. -Educate professionals in the family centered concept. -Hire parents as Title V staff.	-Persistence in conducting assessment and evaluation based on a medical model. -Reluctance of sufficient number of families to participate in state and regional committees.	-Full implementation of the service coordination model on September 2000. -Ongoing continued education regarding family-centered practices to the staff of Pediatric Centers. -Gradual transition from medical to family centered model of services since the EIP. -Integration to the curriculum of medical schools and allied professions. -Revise training curriculum of EI services coordinators and Title V case coordinators to include competencies for family centered services.

Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Gather Not Available Data
	Yes	No			
15) The rate (per 100,000) of suicide deaths among youths 15-19.		X	-Implementation of a comprehensive adolescent program in partnership with the Department of Education. This program includes a training component for selected school staff regarding the identification of youth at risk. -The participation of MCH staff in a Steering Committee charged with the responsibility for developing a plan aimed at reducing suicide deaths in the Island. -Establishment of a pilot program for suicide prevention supported with Title V funds in 2 public schools. -A Commission was established by law, charged with the responsibility of developing a strategic plan to deal with this health issue. -The Secretary of Health appointed a Committee that has been developing an action plan to prevent suicides in PR. -ASSMCA has been training health professionals, teachers, parents and students aimed at the identification, early intervention and appropriate referral of identified cases to available community services.	-Lack of adequate training of primary providers for proper identification and referral of youths at risk. -Nonexistent prevention programs starting in elementary schools. -Need of fiscal resources.	-By September 30, 2001, continue training primary providers on adolescent issues, including the identification and referral of youths at risk of suicide to appropriate services. (This activity was already started). -Conduct a Suicide Conference in August, 2000 with the purpose of creating awareness regarding this problem and to gather input from participants for the action plan.

Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Gather Not Available Data
	Yes	No			
16) Percent of very low birth weight live births.		X	-To promote early and regular prenatal care. -Provision of home visiting services for pregnant women at risk. -In collaboration with the health insurance companies, provide continuing education on alcohol, tobacco and other drugs to the network of primary providers. -Continue with the implementation of an Alcohol Screening Demonstration Project.	-Pregnant women are not aware of the early signs of pregnancy. -High percentage of unplanned pregnancies. -Lifestyle associated risk factors among pregnant women (alcohol, tobacco and other drugs). -High number of pregnant women subjected to domestic violence.	-By September 30, 2001, repeat the TV campaign aimed at increasing the first trimester prenatal care admission rate. -By September 30, 2001, conduct at least 6 sessions of continued education on alcohol screening. -By September 30, 2000, finish the case and control study regarding the factors associated to LBW in PR through the School of Public Health.
17) Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates.		X	-Home visiting services for at risk pregnancies.	-Lack of awareness regarding early signs and symptoms of premature delivery among patients and some health professionals. -Travel time (long distances) from the residence of the mother to the institution with a NICU. -Poor identification of at-risk cases by the patient and their primary providers.	-Ongoing dissemination of educational materials for patients and providers. -By September 30, 2000, complete the study aimed at identifying the reasons for delivery with inappropriate facilities and develop an action plan according to the findings.

Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Gather Not Available Data
	Yes	No			
18) Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.		X	-Promotion of early entry into prenatal care through a TV campaign, posters and dissemination of educational materials. -Dissemination of the public policy aimed at admitting the pregnant woman into service as soon as she requests care.	-Pregnant women are not aware of early signs of pregnancy. -Some professionals do not initiate care as soon as requested. -High percentage of unmarried pregnant women. -High percentage of adolescent pregnancy. -Fear of some pregnant women to the physical examination.	-Ensure that all providers of prenatal care have received the public policy aimed at enforcing admission into prenatal care during the first trimester. -Continue the promotion of early entry into prenatal care at the community level. -Identify and address barriers to early prenatal care.

Accomplishment of State Performance Measures					
Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Get Not Available Data
	Yes	No			
1) The number of HIV positive pregnant women.	X		-The Department of Health has established a public policy aimed at providing pre-counseling, testing and treatment with ZDV to all pregnant women on a voluntary basis. -Development and dissemination of guidelines for treatment of HIV positive women and their infants. -Establishment of a ZDV therapy Advisory Committee responsible of reviewing the progress and monitoring the obstacles in the implementation of ZDV guidelines. The MCH staff belongs to this committee. -Training of primary providers. -Availability of AZT for all identified patients irrespective of their economic status. -Development of an educational video. It has been forwarded to 40 agencies that are committed to its dissemination.	-Difficulty to reach all primary providers in areas of the HCR in a short period of time. -Some prenatal care providers do not follow established standards of care.	-Ongoing site visits to the health regions to monitor the implementation of guidelines for pre counseling, testing and treatment with AZT. -Ongoing continued education for prenatal providers. -Develop mechanisms to assess the degree of compliance with prenatal care guidelines.

Accomplishment of State Performance Measures					
Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Get Not Available Data
	Yes	No			
2) Establish a Home Visiting Program for at-risk pregnant women and children less than 3 years in at least 95% of the municipalities by the year 2000.	X		-Availability of registered nurses who can be recruited with Title V funds while funds are available. -A significant proportion of the home visiting nurses are very motivated with the new tasks. -Support of the Healthy Start program to pay the salary for central level staff: Coordinator, Health Educator and Evaluator. -The MCH program is supported with Healthy Start funds for the replication of the case management/care coordination model.	-Need for funds to relocate the appropriate number of Home Visiting nurses according to the anticipated number of clients in each municipality.	-By September 30, 2001, implement the Home Visiting Program in at least 76 municipalities. -To provide a one-week training for all new home visiting nurses to ensure quality and uniformity of services provided. -To continue the relocation of nurses. -Training to identify children 0-3 years of age with developmental delays for referral to Early Intervention Program. -To update norms and procedures according to the Home Visiting evaluation performed in January 2000.
3) The incidence rate of NTD's.	X		-Incidence of NTD has decreased to 0.8/1,000 live births. -The CDC provides the salary for a Visiting Fellow. -Collaboration of the private sector, media, the Department of Education, the WIC program, the School of Medicine, associations and other entities. -Quality of the educational materials, which include 2 posters and 4 original brochures.	-Need for fiscal resources to implement established activities. -Attitudinal barriers among physicians. -Need of funds to implement a folic acid curriculum at all school levels.	-Refocusing the campaign geared towards changing attitudes of adolescent women in view of NTD's risks by maternal age, in collaboration with the Department of Education. -Elaborate an instructional module for elementary school in collaboration with DOE.

Accomplishment of State Performance Measures					
Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Get Not Available Data
	Yes	No			
			-Recruitment and training of 5 abstractors (LPN's). -Elaboration of an instructional module for junior and high school students considered as outstanding by CDC. -Promotion in Spanish of the campaign messages included in two sizes of the best selling cereals in PR. -Incorporation of private insurers for the Health Reform to the educational phase of the campaign. More than 20,000 professionals and others were trained, not including Health Reform providers. -Development of an educational video. -More than 600 teachers of the Department of Education have been trained to start a curriculum regarding the use of folic acid. -Promotion of the campaign messages in more than 1 million packages of "Arroz Rico" (Brand of rice used in PR).		

Accomplishment of State Performance Measures					
Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Get Not Available Data
	Yes	No			
4) Developing a surveillance system for selected birth defects	X		-Collaboration of the CDC with the assignment of a Visiting Fellow. -Regional perinatal nurses serve as basic resources for data collection in all regional hospitals. -Collaboration of all private birthing hospitals, collecting and submitting NTD's data to the central level. -Five licensed practical nurses were recruited to carry out chart review through all birthing centers. -Collaboration of two fetal evaluation and high-risk pregnancy programs that inform prenatally diagnosed and pregnancy termination due to NTD's. -The surveillance system has corroborated that PR indeed, has a very high incidence of NTD's.	-Need for additional personnel at Central level to coordinate campaign efforts geared toward other defects.	-This epidemiological surveillance system started with NTD's. It included cleft lip and palate surveillance in January 1999. In January 2000, other birth defects were included. -The data collection instrument was revised to include cleft lip/palate defect. -To add additional births defects to the Surveillance System: gastroschisis, clubfoot, limb defects and Down Syndrome.

Accomplishment of State Performance Measures					
Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Get Not Available Data
	Yes	No			
5) Prevalence of tobacco use among pregnant women.	X		-Collaboration of the Department of Epidemiology and Biostatistics of the School of Public Health in determining the prevalence of tobacco use and other risk behaviors among pregnant women in PR. -Recruitment of an Epidemiologist. -Development of a customized PRAMS questionnaire.	None.	-To survey a representative sample of pregnant and postpartum women enrolled in the WIC program on an ongoing basis. -A case control study has already started aimed at determining factors of LBW in PR. -To institutionalize the ESMIPR Surveillance. This is a customized PRAM Survey performed with Title V funds.
6) The birth rate among girls 10-14 years of age		X	-The development of an Abstinence Education Only Program implemented since August 1998 in grade 5th - 12th. This is a joint effort of the Departments of Health and Education.	-Cultural barriers, which impede sex education to children and adolescents. -Lack of skilled professionals in the area of sex education for children and adolescents. -Lack of legislation to allow primary health providers to serve adolescents without parental or guardian consent.	-To continue the abstinence education only program. -To monitor the birth rate among girls 10-14 years of age by municipality on a regular basis. -To obtain results of the YRBS (1999) by December 2000. -To establish a pilot program aimed at reducing repeated pregnancies in the municipality of Loiza in collaboration with the School of Nursing of the UPR.

Accomplishment of State Performance Measures					
Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Get Not Available Data
	Yes	No			
7) The rate of deaths to children aged 1-14 caused by asthma.		X	-Availability of data from ASES related to ER visits, hospital admissions and office visits, which serve as indicators of outcomes for the established plan. -Collaboration of health insurance companies in developing prevention strategies, including cost containment benefits. Triple C is recruiting an Asthma Coordinator to work in collaboration with our Asthma Educator. -Interest showed by pharmaceutical companies for the education of physicians, patients and families. -The Asthma Coalition has established collaboration between Title V, the Pediatric Pulmonary Program of the Pediatric University Hospital, the School of Medicine, MCO and ASES to educate parents, children, allied professionals and primary providers so as to better serve patients with asthma. -Implementation of the "Colores del Asma" pilot project since December 1999 in Bayamón. -The Pediatric Pulmonary Program at the Cardiovascular Hospital has served 100 families and children since August 1999. -MCH has provided TA for PR Asthma Summit to be held on September 21, 2000.	-Bronchial Asthma not previously included in the list of conditions of CSHCN in PR. -Poor attendance of physicians at educational activities. -Reluctance of primary providers to refer patients to subspecialists. -Availability of state of the art medication through GIP, but not prescribed by primary physicians.	-Continue the planning and implementation phases started in July 1998. Task force is already working. -Funding of a nurse, a social worker, a secretary, a nutritionist and a health educator by the Secretariat for Health Promotion and Protection. -To implement the plan aimed at reducing the morbility and mortality due to asthma with the support of Region II.

Accomplishment of State Performance Measures					
Performance Measure	Meeting of the Target		Role of Title V and Other Agencies on Meeting the Target	Barriers to Meeting the Target	Plans to Get Not Available Data
	Yes	No			
8)Developing standards of care for CSHCN.	X		-Provide guidelines to primary physicians and indications for referral to sub specialists. -Standards of care can be used as criteria when calculating risk adjustments. -The collaboration of the specialized staff of the Pediatric Centers.	-Expert panel members have time limitations to participate in task forces.	-Start with the five most common diagnoses seen at Pediatric Centers. -To finish the 5 protocols by March 2003.

2.5 Progress on Outcome Measures

The annual outcome measures row was updated with the latest, final or provisional available data (Form 12). Table 6 summarizes the baseline data in 1991 compared with the latest data. It clearly demonstrates that Puerto Rico is moving towards the targets on all outcome measures.

TABLE 8

Outcome measure	Baseline 1991	Latest data 1998	Percent of Change	Target 2010
1. Infant Mortality	13.0	10.5	-19.2	6.9
2. Infant Disparity	-	-	-	-
3. Neonatal Mortality	9.7	7.4	-23.7	5.8
4. Post Neonatal Mortality	3.3	2.8	-15.2	2.2
5. Perinatal Mortality	17.1	16.8	-1.8	15.80
6. Child death Rate	24.7	22.4	-9.3%	11.7
7. Maternal Mortality (SOM)	13	5.0	-61.5%	6.0

Note: N/A= Not available, NMR: Neonatal Mortality Rate, FDR: Fetal Death Rate

A broad array of sociodemographic, biological, environmental and behavioral risk factors impact on the outcome measures established to monitor the health status of the MCH population. Although access to quality health services is very important in dealing with health conditions such as anemia, hypertension, diabetes and urinary tract infections, the problem is more than a medical one. However, it appears that it is a social problems and their health consequences, which are negatively affecting the outcome measures in Puerto Rico. According to the last Census (1990), close to 60% of the population was under the poverty level. On the other hand, in 1998, 46.9% of all live births were to unmarried women, 20.4% to adolescents, and 28.2% of the mothers had not completed high school education.

Regarding behavioral risk factors, a significant number of pregnant women exposed their unborn infants to the effect of alcohol (4.8%), tobacco (4.8%), other drugs (3.5%) and 6.2% had a lifetime history of physical abuse by the husband or partner, as found in an Islandwide survey performed in 2000. Obviously, most of the factors that negatively affect the outcome measures are outside the control of Title V.

However, Puerto Rico has achieved several performance measures that can help to reach the target of outcome measures. These are the following:

1. The percent of newborns with at least one screening for each PKU, hypothyroidism,

galactosemia and sickle cell anemia (96.4%).

2. The percent of children through age 2 years who have completed immunization: 93.7%.
3. Percent of children without health insurance. As of July 2000, more than 95% of the children living in the Island should have a health insurance paid by either the Government or a private company.
4. PM #6 – The rate of births (per 1,000) for teenagers aged 15-17 years: 51.9/1,000 (1998).
5. SPM #1 – The number of HIV pregnant women treated with AZT: 100% (1999).
6. SPM #2 – Establish a Home Visiting Program in at least 90% of the municipalities comprising the Island: 92.3% (1999).
7. SPM #3 – The rate of neural tube defects: .91/1,000 (1999).
8. SPM#6 – The birth rate among girls 10-14 years of age: 2.2/1,000 (1998).
9. SPM#7 – The rate of deaths to children aged 1-14 years caused by Asthma: .2/100,000 (1998).

Our challenge is to struggle with the external factors outside the control of Title V in partnership with the other entities and the population itself. Therefore, the work plan contained in this application is geared to address many behavior factors associated with preterm births and low birth weight that are the determinant variables of the infant mortality rate.

III. REQUIREMENTS FOR THE APPLICATION (Section 505)

3.1 Needs Assessment of the MCH Population

3.1.1 Needs Assessment Process

Methodology: A needs assessment team comprised of 14 key staff members of the MCH (7) and the CSHCN (7) programs was convened by the MCH Director.

The team used the MCH Year 2010 Objectives of focus areas number 5 (Family Planning), and number 16 (MCH); the 18 national and the 8 negotiated state performance measures; the 23 health indicators and the 6 national and the one state outcome measures to guide the needs assessment process.

The process to gather required information to assess the needs of the MCH population was as follows:

1. Reviewing the new guidelines emphasizing the minimal data required for assessing performance, outcome measures and the new health indicators.
2. Preparing a list of the type of data required: demographic, socioeconomic, environmental, health status, health services, resources, services utilization, surveys and studies related to MCH issues.

3. Preparing a list of possible sources of primary and secondary data.
4. Requesting the available information in writing or through personal contacts.
5. Participating in interagency committees, task forces, coalitions, and interagency meetings where MCH issues are presented and discussed.
6. Performing patient surveys to determine reasons for late entry into prenatal care.
7. Performing an islandwide chart review of all (n=15,531) Home Visiting Program participants who were active through calendar year 1999.
8. Determining the human resources by examining the payroll to identify the number and classification of positions supported by Title V funds.
9. Performing a descriptive analysis of all infant deaths (n=637) registered in 1998.
10. Performing a customized CDC PRAM Surveillance among post partum women in 18 randomly selected birthing hospitals (n=2,230). The purpose of this surveillance was to determine the prevalence of behavioral risk factors, prevalence of breastfeeding and pregnancy outcomes.
11. Conducting several special studies to better understand certain MCH health issues. These included but, were not limited to:
    a. Descriptive study of all cesarean sections occurred during the period 1990-1998 (n=21,224)
    b. Descriptive study of all related maternal deaths during the period 1991-1998 (n=510,073)
    c. Analyzing all LBW occurred during 1998 (n=6,615)
    d. Analyzing deaths due unintentional injuries occurring in 1998.
    e. Case study of VLBW infant born outside level III hospitals.
12. Collecting data from Medicaid upon certification for the GIP for the identification of CSHCN, as well as data from children served by the State Program and the source of insurance, data from ASES, Head Start and private and privatized hospitals.
13. Conducting focus groups among adolescents regarding the issues of sexual activity and adolescent pregnancy.
14. Conducting focus groups at Pediatric Centers with families of CSHCN to gather their input regarding their perceived health needs and health system barriers.
15. Consolidating all collected data into tables and graphics to facilitate the analysis and determination of health needs and priorities that should be addressed in the action plan according to available resources.
16. Designing an Integrated Health Index (IHI) to assess the MCH health status by municipality. The IHI was comprised 15 selected indicators.

The community and other stakeholders input was obtained through focus groups that were held with adolescents, the SSDI Regional Working groups, focus groups with families of CSHCN, meetings with the MCH (Healthy Start) Consortium, and through participating in different interagency committees/meetings and coalitions.

Priorities were developed based on the data analysis, number of persons affected and input from stakeholder groups.

The plan was made available to the general public to request additional comments of the final draft (**Appendix 7**).

The major strength of the process was the wide participation of first line MCH providers such as the Home Visiting nurses, outreach workers, the MCH/CSHCN regional directors and coordinators (SSDI), the MCH central staff, families of CSHCN, the Assistant Secretariat for Planning, Evaluation, Statistics and Information Systems, the Demographic Registry, ASES, Medicaid and a large number of directors of other programs and entities that serve the same MCH population.

The major weakness of the process was the poor response of the general public which did not show up to evaluate the final draft of the MCH needs assessment and plan. It is important to highlight that this is the usual response of the general public if there are no funds to distribute. However, there was good response of the parents of CSHCN islandwide invited to participate of the focus groups.

3.1.2 Needs Assessment Content

3.1.2.1 Overview of the Maternal and Child Health Population Status

The data compiled from different sources were analyzed to assess the health status for each subgroup of the MCH population. For the purpose of this description the following four subgroups are considered: (a) Pregnant women, mothers and infants; (b) Pre-school and school aged children; (c) Adolescents and (d) CSHCN.

Priority health problems, health services gaps, system constraints, strengths and weaknesses were identified for each of the above-mentioned subgroups.

A. Pregnant women, mothers and children: Factors contributing to maternal and infant morbidity and mortality may be classified into four main groups (**Figure 12**):

1. Sociodemographic factors

According to the Census Bureau (1990), the percentage of families and individuals under the poverty line was 58.9%. Twenty-three percent of all households with no husband present were headed by a single woman of childbearing age; and 51% of these females had children under 18 years of age. In 1998, the average family income in the Island was $6,266. The per capita personal income was $9,930 (1999), quite below the U.S. and the Mississippi averages. In 1999, the unemployment rate was 10.5%, compared to 4.4% in the U.S. The medically indigent population represented almost 46% (1.8 million) of the total population. As of December 1999 the number of women in their reproductive age (15-44) and infants who hold the Government Insurance Plan amounted to 368,659 and 49,138, respectively.

In 1998, 20.4% of live births were born to adolescents and almost 7.3% to women 35 years old or over. Among all births, 46.9% were to unmarried women. In adolescents, 7 out of 10 gave birth out of wedlock. The proportion of women who had attained less than high school education at the time of delivery is decreasing (28.2%), but it is still high. There are a significant number of women with poor educational attainment, placing them in social and economic disadvantages. All these

are risk factors contributing to the birth of children with increased potentials to have developmental delays and/or disabilities.

2. Maternal Health Problems and Lifestyles

In Puerto Rico close to 7 out of 10 pregnant women are enrolled in the WIC program. This is an indicator of nutritional risk factors. In FY 1998-99, the most common reasons for WIC participation in order of frequency were anemia, obesity/underweight and adolescent pregnancy. Other frequent conditions found among participants were recurrent pregnancy and nutritional related problems. As many studies have demonstrated worldwide, women who practice unhealthy behaviors are more likely to have LBW infants. These seem to be important factors currently affecting a significant number of expectant women in our Island.

Results from a cross-sectional study of postpartum women from a representative sample of 18 birthing hospitals across the Island showed that 4.8% of the women smoked, 4.8% used alcohol and 3.5% used illicit drugs during the first trimester of pregnancy. History of physical abuse at some time during their lifetime by their husband or partner was reported by 6.2% of all women who answered the self-administered questionnaire (2000). In 1997, ASSMCA served 306 drug addicted pregnant women, compared to only 176 cases in 1999. However, this drop in cases cannot be interpreted as a reduction in the prevalence. It is important to understand that due to the Health Care Reform many of the cases would have been treated in the private sector. Data of the SIVEMI showed that 61 live births were diagnosed with fetal alcohol syndrome in 1998, compared to 35 in 1996.

Having sexual intercourse with partners infected with HIV and other sexually transmitted diseases (STD) constitute behaviors and lifestyle factors which contribute to the escalating rates of LBW, which is the most important determinant of infant mortality. As a matter of fact, in 1993 seven infants died secondary to AIDS, and only one in 1999. A total of 83 women were identified as HIV positive during 1999; all of them received adequate treatment therapy. Among the infants of these 83 mothers, only one was diagnosed as a case of AIDS. In 1998, 29 cases of congenital syphilis were reported across the island. In addition, 78.9% of all cases of chlamydia in 1999 were women among the age group 13-39 years old.

3. Prenatal and Perinatal Factors

In 1998, the total number of registered live births was 60,518 and the natality rate reached 15.8 per 1,000 inhabitants, being the lowest level ever recorded. Almost all (98.8%) live births occurred in hospitals, 35.1% by cesarean section. It is estimated that close to five percent (over 3,000) infants needed level II or III neonatal care in 1998.

Singleton births accounted for 59,460 (98.3%); twins were 1,034 (1.3%) and higher order births reached 24 (0.04%).

One out of five (20.4%) infants were born to adolescents and 8,591 (70%) of them became mothers for the first time. The proportion of infants born to adolescents had been increasing since 1988. A decline of 1.5% in 1998 of live births to adolescent mothers, compared to 1997 data was observed (**Figure 13**). On the other hand, women over 35 years of age gave birth to 4,406 (7.3%) infants.

Overall, 46.9% of births occurred out of wedlock and in the case of adolescents the percentage of unwed mothers climbed to 72%. The ESMIPR Surveillance conducted by the MCH Division showed that 60% of postpartum women surveyed did not plan the last pregnancy. A significant proportion of these children will be subjected to negligence and child abuse. The proportion of women with less than 12 years of education shows a decreasing tendency (28.2%), but is still high.

The evaluation of the source of payment of all live births showed that 41.4% (25,051) had the GIP (up to 200% state poverty level); 38.5% (23,270) had a third party payer, 18.4% (11,126) were pure Medicaid, 0.2% (141) unknown, 0.1% (73) charity, and 1.4% (857) out of pocket. This variable seems to be a proxy of the socioeconomic factor and should be considered when analyzing the pregnancy outcomes in Puerto Rico.

The first trimester admission rate was 78.6% and the adequacy of prenatal care measured by the Kottelchuck Index was 67.26%. Less than one (1) percent (599) received no prenatal care at all.

Maternal age, civil status, education, health insurance and adequacy of prenatal care are some of the independent variables that have an impact on birth outcomes and infant mortality.

Prematurity and low birth weight are the most important determinant variables of infant mortality. In 1998, the proportion of premature births was 14.2%, the LBW was 10.9% and the VLBW was 1.33%. The population of LBW babies is comprised of two groups: those who are born before the completion of 37weeks of gestation and those who are +37 weeks of gestation. In 1998, 56% of LBW were premature versus 44% that were born at term.

Low birth weight impacts the infant's survival and future development. LBW infants have a 40 times greater risk of dying in the neonatal period than normal weight babies, and VLBW infant are 200 times more likely to die than normal weight babies. Underlying causes of infant death have social and economic roots requiring close collaboration among health and human service programs at state and local levels. A significant number of infant deaths remain preventable through public health activities.

In 1998, the Puerto Rico infant death rate reached 10.5 per 1,000 live births. This is still 1.5 times higher than the US rate (7.2) for the same year. The absolute number of registered infant deaths was 637. It was found that males were 1.3 times (56%) more likely to die during the first year than girls. Over one third of all infant deaths occurred in those born to women at the extremes of their reproductive age. Women under 19 years of age contributed with 26.2% of all infant deaths while those 35 years or older contributed with 7.3%.

Infants born at 32 weeks of gestation or less represented 2% of all live births. However, this 2% contributed 73.8% of all infant deaths. Preterm births were 2.8 times more likely to die during the first year. Overall, 73.7% of all infant deaths were LBW and among these 56% were <1,500 grams.

In 60% of all infant deaths, the mother was unwed or separated.

Nearly two thirds (62.5%) of all infant deaths occurred in the early neonatal period, and 73.2% during the neonatal period. Only one out of four (26.7%) occurred in the post-neonatal period (**Figure 14**). All accidents were the 11th cause of infant death. Sixteen infant deaths due to accidents were registered. Many of these deaths could be prevented. Sudden infant death syndrome is not a common cause of infant mortality in Puerto Rico. In 1998, only 6 SIDS cases were reported.

4. Post neonatal Factors

In order of frequency, the leading causes of infant deaths in Puerto Rico in 1998 were the following: (1) short gestation and LBW (29.5%); (2) congenital anomalies (18.8%); (3) respiratory distress syndrome (14.3%); (4) other respiratory conditions (6.3%) and (5) pneumonia and influenza (2.7%).

During the post-neonatal period, the first cause of infant deaths is congenital anomalies, followed by short gestation and LBW. It is important to highlight here that a significant number of these post neonatal deaths represent infants who survived because of the use of technology.

Fetal Death

Figure 14 also summarizes the trends of fetal deaths in Puerto Rico. Historically, fetal deaths in Puerto Rico are associated with the following risk factors in order of frequency: (1) hypertension associated with pregnancy, (2) diabetes, (3) incompetent cervix, (4) anemia and (5) chronic hypertension.

Integrated Index of Maternal and Infant Health Status (IIMIHS) by Municipality (Appendix 8).

In order to assess the maternal and infant health status and to compare it by municipalities, an IIMIHS was developed by the MCH Division. Towards this goal, 15 indicators were selected from birth and death files (1998). The IIMIHS is comprised of five sociodemographic indicators, two related with the adequacy of prenatal care and eight reflecting the pregnancy outcome indicators. (Table 9)

TABLE 9

TYPE OF INDICATOR		
SOCIODEMOGRAPHIC	**ADEQUACY OF CARE**	**OUTCOME OF PREGNANCY**
1. Natality rate 2. Percent of unmarried women 3. Percent of adolescent mothers 4. Percent of unmarried adolescent mothers 5. Percent of mothers with less than 12 year of education	1. First trimester admission rate 2. Kottelchuck Index	1. Percent of prematurity 2. Percent of VLBW 3. Percent of LBW 4. Neonatal mortality 5. Postneonatal mortality 6. Infant mortality rate 7. Stillbirth rate 8. Perinatal mortality rate

Methodology: Making use of available data from birth and death files of 1998, the value of each of the 15 indicators was determined for the 78 municipalities. These were ranked according to the value of the indicator. The sum of all the 15 ranks obtained by a municipality constitutes what is called the IIMIHS. In theory, if a municipality ranked in the first position for each selected indicator it would have an IIMIHS of fifteen (15). In the contrary, if it ranked in the last position (#78) for each selected indicator it would have an index of 1170.

Results: After ordering the 78 municipalities by the integrated value of all 15 indicators it was found that the 10 best municipalities were 1) Aguadilla; 2) Aguada; 3) Hormigueros; 4) Rincón; 5) Las Marías; 6) Añasco; 7) Isabela; 8)Camuy; 9) Ceiba; and 10) San Sebastián. On the other hand, the worst 10 municipalities were: 1) Luquillo; 2) Patillas; 3) Guayanilla; 4) Yabucoa; 5) Aguas Buenas; 6) Guánica; 7) Jayuya; 8) Maunabo; 9) Loíza; and 10) Cataño. It is expected that further statistical analysis will help us to determine which are the indicators that have the higher impact on birth outcomes.

Other MCH Issues

Cesarean Section: Historically, C-section rates in Puerto Rico have been higher than those in the mainland USA (Vázquez-Calzada, 1988). A descriptive study was carried out aimed at providing updated information to concerned individuals and organizations to generate discussion regarding the possible causes that lead to the increased use of this birthing method in Puerto Rico.

Stratified analyses from linked birth and death files provided by the State Vital Statistics Office were performed using the most relevant data available to describe the picture and to generate hypotheses regarding the problem.

A total of 21,224 C-section live births were evaluated for the 1990-98 period. The C-section delivery rate has increased from 31.0% in 1990 to 35.1% in 1998. Primary C-section rates rose from 19.9% to 21.2% (6.5% change) and repeat C-sections increased from 13.5% to 13.9% (3%). Overall, C-section rates vary greatly according to maternal age; in 1998, mothers between 20-34 years old were three times as likely to have a cesarean delivery as teenage mothers (75% and 14.7%, respectively), in contrast to the 1.9% experience observed among women 40 years or over. C-section rates were higher for mothers with private health insurance (44.8%) followed by the ones with the new Government Insurance Plan (32.7%) and then by those with the Medicaid plan (21.5%). The rate of vaginal births after previous cesarean delivery (VBAC) was down 7.7%, dropping from 1.3% in 1997 to 1.2% in 1998. The most prevalent birth complications reported across all the study period were cephalopelvic disproportion (15.9%) and breech presentation (5.3%). Also, hypertension (5.1%), anemia (4.3%) and diabetes (2.9%) were the most common complications found during pregnancy. Among all deaths of infant born by C-section in Puerto Rico, the percent slightly increased from 40.6% in 1997 to 41.1% in 1998, contrary to the steady decline observed among deaths of infants born by vaginal route for the same years (59.3% to 57.8%). Tuesdays (18.3%) followed by Wednesdays (17.8%) were the most frequent days and Sundays (6.7%) followed by Saturdays (8.4%) were the least frequent for C-sections and the majority of the procedures were performed in the afternoon (56.9%). The procedure was performed more frequently between 12:00 and 6:00 PM. The proportion of C-sections ranged from 9% to 69% at different birthing centers. These findings suggest that convenience may be an underlying factor for the increase in C-section rates in Puerto Rico.

This study is expected to promote general awareness of the problem among OB/GYN specialists and the Association of Hospitals to help them to develop policy and practices aimed at reducing C-sections in Puerto Rico.

Maternal Mortality: Since 1956, the maternal mortality ratios (MMR's) have declined 95% in Puerto Rico according to vital statistics reports. However, maternal mortality (MM) continues to be an important public health problem that affects the individual, the family and the overall society. Reports of maternal deaths based on death certificates are usually underestimated. Actual numbers are two to three times greater.

Several studies had identified under-reporting of maternal deaths in Puerto Rico due to misclassification of the cause of death. In 1982, Comas and others found 71.4% under-reporting of maternal deaths. These and other studies led to the inclusion of checkbox No. 21 in the death certificate in 1989. This checkbox helps to identify women who have been pregnant at the time of death or during the 12 months prior to death.

According to vital statistic reports from 1990 to 1998, the number of maternal deaths fluctuated between 4 and 14. However, it is important to highlight that these deaths occurred around the perinatal period and represent the most severe pregnancy complications leading to maternal deaths (1CD9 Codes N630-N676.9).

Maternal and infant mortality are basic health indicators that reflect the nation's health status and well being. Current MMR's are unacceptable, not only in Puerto Rico, but also in the mainland, considering the amount of resources and technology invested in health care services. Since 1982, no progress has been made in the U.S. towards achieving the H.P. year 2000 goal based on data of 1987 of 3.3 maternal deaths per 100,000 live births. In fact, preliminary data for 1997 showed MMR's of 7.7 and 5/100,000 live births in the U.S. and Puerto Rico, respectively.

To better understand the underlying causes of maternal deaths in PR a descriptive study was carried out at the PR MCH Division. This study will help us in developing strategies aimed at improving this health indicator.

During the study period (1991-98) a total of 510,073 live births and 75 maternal deaths were reported in Puerto Rico. This represents an average of 14.7/100,000 maternal deaths for the period. However, the investigators (Roberto Varela Flores, MD, MPH, Cristóbal Cintrón, MS and Himirce Vázquez, MD) could identify 149 associated maternal deaths, representing an average of 29.1/100,000 live births with a discrepancy of 50 percent as compared with data from vital statistics.

Most maternal deaths were distributed in two geographical areas: in the northeast and in the south. Of the 149 associated maternal deaths, 44.3% (66) occurred after a live birth, 8.1% (12) after stillbirths, 6% (9) after abortion, 2.7% (4) after ectopic pregnancy and 38.9% (58) were unknown or other outcomes.

The interval between the time of birth or pregnancy termination and death of the mother was known in 86% of the cases. Eighty-eight (59.1%) of the mothers died during the postpartum period, 28 (18.8%) while pregnant and 12 (8.1%) during labor and delivery.

Regarding selected socio-demographic characteristics, it was found that 54.1% of mothers were in the extremes of the reproductive age (<19 or >35 years of age), 41.6% had attained less than high school education, over fifty percent (51.7%) resided in rural areas, 55.7% were married, 37.6% unmarried, 4.7% divorced and 2.0% separated.

The five leading causes of deaths were postpartum hemorrhage (16.1%), thrombotic pulmonary embolism (11.4%), sepsis (9.4%), CNS insult (8.1%) and disseminated intravascular coagulation (6.0%).

Domestic Violence: Domestic violence is an alarming and complex public health problem in Puerto Rico. This statement is supported by selected sociodemographic data, MCH health indicators, data from the Police Department and two islandwide studies using pregnant women as the target population. One of these studies looked at the nature and extent of domestic violence inflicted by partners. The findings of this study were staggering, showing a prevalence of 34.8% of pregnant women subjected to domestic violence by their partners (A. de Jesús, 1994). The second study examined the prevalence of certain risk behaviors among pregnant women including the problem of domestic violence. (1998)

This public health problem is a concern for government officials, legislators, women's advocacy groups, health professionals and the public at large. In fact, the issue is frequently brought to public attention through mass media communications in headline news. However, in spite of the well-documented needs and awareness regarding the problem, programs and services for addressing this issue are limited due to the lack of fiscal resources. In addition, there is a need of a well coordinated and concerted action plan between the evolving health care system in Puerto Rico, other public agencies and community intervention programs concerned with the provision of services to victims of domestic violence during or around the time of pregnancy. Towards this goal, the Office of Women's Affairs has established an Interagency Task Force and developed a training program aimed at implementing a Domestic Violence Management Protocol. The current system for screening, routinely assessing, preventing, referring and directly intervening in cases of domestic violence is quite deficient. The only programs that screen, assess and coordinate services among entities and programs concerned with intervention of domestic violence cases are the Home Visiting Program of Title V and the Rape Crisis Center (RCC). Unfortunately, our health professionals' training and skills in the area of domestic violence are limited.

Smoking, alcohol consumption, drug abuse, domestic violence during pregnancy and sexual intercourse with infected partners are behaviors and lifestyle factors that contribute to the escalating rates of LBW, infant morbidity and mortality in Puerto Rico. As many studies have demonstrated worldwide, women who practice unhealthy behaviors are more likely to have LBW infants. These seem to be important factors that are currently impacting an unknown but significant number of expectant women in our Island.

During the decades leading to the turn of the century, the issue of domestic violence against women by intimate partners has changed from being considered a private or taboo matter to being recognized as a large public health problem with underlying causes and consequences not only for the victims, but also for the society in general. This is a very complex public health problem that requires the partnership of a variety of public and private entities in developing strategies for improving systems of care to be effective in the prevention, identification, and management of victims as well as in developing public policy.

Several research studies suggest that women may be at higher risk of domestic violence by intimate partners around the time of pregnancy. Therefore, pregnancy provides a window of opportunities for the identification and management of abuse against women. This is so because women usually come in contact more frequently with the health care system during pregnancy. However, primary health care providers (MD's, RN's, social workers, nutritionists, and others) need to be very well trained to appropriately perform screening for domestic violence at all their interventions. Data from the Police Department and two studies with pregnant women across the Island demonstrate that domestic violence during pregnancy is an alarming situation in Puerto Rico.

Since the enactment of the law for the Prevention and Intervention Against Domestic Violence, this issue has been brought into public attention. (Law #54 of August 15, 1989). As shown in **Figure 15**, there is an escalating trend of domestic violence reports to the Police Department since 1988. During the last 10 years the percentage of incidents reported has increased in 46%. **Figure 16** illustrates a similar trend in the request for protective orders. **Figure 17** demonstrates the distribution of domestic violence reports by Police Areas for 1990-1999. It shows that Bayamón and San Juan have the highest number of incidents reported, while Aguadilla has the lowest.

Evaluating the data collected by the Police, it is found that there are 9 female victims of domestic violence for each male. In fact, the average number of women killed by their partners (spouse, ex-spouse, boyfriend, or partner) per year is around 29, versus five men killed by their female partners. This represents a proportion of six women to each man killed by their respective partners.

In addition to the selected sociodemographic data, perinatal data and the Police reports on domestic violence, two recent studies of pregnant women across the Island underscore the problem of domestic violence in Puerto Rico. Angela de Jesús, Ph.D., carried out the first investigation on this issue in 1994, as her requirement to earn her doctorate degree in Public Health Education. Twenty-five (out of 84) public prenatal clinics were randomly selected across the Island to participate in the study. The purpose of the study was to explore the nature and extent of physical, sexual and emotional abuse against pregnant women in Puerto Rico. The target population was all pregnant women from 12 to 40 years of age who received prenatal care services in the selected clinics. The research used a self-administered questionnaire: "An Estimate of Victimization of Pregnant Women" (EVPW). The questionnaire consisted of 17 items related to demographic information, 20 items aimed at estimating the prevalence and frequency of the different manifestations of abuse. The last section included body maps on which the women could indicate the site or body areas where physical abuse had been experienced during current or previous pregnancies.

A total of 1,695 questionnaires were distributed throughout the 25 randomly selected prenatal clinics. From this figure 1,616 (95.3%) pregnant women completed and returned the

questionnaire. The findings were staggering. It was found that over one-third (34.8%) of the respondents had been abused during current or previous pregnancies. This means that one in three (1:3) pregnant women in Puerto Rico was victim of physical, sexual or emotional abuse inflicted by their intimate partner (or guardian in case of adolescents). Even worse, the abuse was not an isolated incident, but rather a frequent event. Adolescents with low educational attainment and low family income were at higher risk of abuse.

The highest incidence of abuse (21.9%) was found in the Northern Health Region of Bayamón, while the lowest (1.2%) was reported in the western Health Region of Aguadilla. The abuse was most frequently reported to occur during the second and third trimesters of pregnancy (41.3%). In terms of time of the day, it occurred most frequently at the night (58.4%).

Among the 562 abused pregnant women, 90% indicated that they were victims of emotional abuse, 63% physical abuse, and 28% were sexually abused. The five (5) signs and symptoms of emotional distress most often reported by respondents were: emotional abuse caused by the intimate partners (83.6%), feeling depressed (75.1%), becoming repulsed toward their partners during sexual relations (60.5%), feeling shy (56.2%) and developing low self-esteem (51.1%).

The leading types of physical abuse in decreasing order of frequency were: being slapped, being hit with a fist, being pushed, incurring in black and blue marks, being forced to have sexual relations, being kicked, being shaken, being threatened with a knife, being threatened with a gun, suffering an abortion, experiencing fractures, and being burned. These types of physical injuries occurred primarily during the current pregnancy.

Another local study was conducted in Puerto Rico in 1998. The Division of MCH prepared a Spanish-language short version of the CDC PRAMS questionnaire, selecting those items related with tobacco, alcohol, illicit drug use and domestic violence. The instrument was self-administered to a representative sample (n=662) of WIC participants Islandwide.

It was found that among the respondents, 4.8% were smokers, 4.6% consumed alcohol, 1.7% used drugs and 6.2% had experienced physical abuse by intimate partners. Considering that 60,518 live births were registered in PR in 1998, we can estimate a significant number of women (10,450) who were engaged in risk behaviors and domestic violence. These behaviors seem to be important contributors to the increasing rates of LBW and premature births in Puerto Rico.

The table that follows (Table No. 10) depicts behavioral factors and their associated risk for premature delivery in previous pregnancies. Statistics of WIC participants found that women who were subjected to domestic violence were 2.7 times more likely to have a premature infant.

TABLE 10

Associated Risk Factors with LBW and Premature Births Puerto Rico, 1998		
Risk Factor	**Odds Ratio**	**95% CI**
Physical Abuse by Partner and LBW	2.7	1.1 – 6.2
Smoker 1st Trimester and Preterm	3.8	1.4 – 9.8
Smoker 1st Trimester and LBW	2.8	1.1 – 7.1
Physical Abuse and Preterm	2.1	0.8 – 5.5

In view of these statistics, it becomes clear that to decrease infant mortality and morbidity in the Island we must intervene to eliminate or at least ameliorate the lifestyles and high-risk behaviors in which our pregnant women engage. Therefore, developing, establishing and implementing the practice of universal screening for alcohol consumption, smoking, illegal drug use in pregnant women as well as for domestic violence is a worthwhile endeavor in trying to decrease IM and women's homicides. This intervention should be included as part of the standards of care for prenatal care. It is important to mention here that the Puerto Rico Department of Health submitted a proposal requesting support to implement a program for training primary providers for universal screening for domestic violence during prenatal care. Unfortunately, the proposal was not approved in spite of the well-documented need.

The adverse effects of domestic violence during pregnancy have been documented in the scientific literature. However, the practice of universal screening for domestic violence during prenatal care visits is not performed by most medical providers as part of the routine health care of the pregnant women. Although the public health sector is keenly aware of the importance of the universal screening and the economic benefits of preventing domestic violence, one of the most difficult barriers to implementing universal screening for domestic violence is motivating the medical providers to adopt this intervention in their practices. Medical providers are often oblivious to the importance of public health issues such as universal screening for substance use and domestic violence and the consequences that an inadequate identification of these risks pose for them and their practice.

B. <u>Pre-school and school aged children.</u>

Size and Composition

As of 1998, there were approximately 1,292,226 children and adolescents ages 19 and under living in PR. The overall size of the child population has declined 3.3% during the past two decades (1980-1998). The only age group that has increased slightly is the adolescent group (15-19 years of age).

TABLE 11
NUMBER AND PERCENT OF CHILDREN OF THE TOTAL POPULATION BY AGE GROUPS

Ages	1970	1980	1990	1998	Percent of Total Population (1998)
1 – 4	251,162	267,592	250,436	261,422	6.8
5 – 9	138,800	330,331	316,991	314,352	8.2
10 – 14	335,100	338,291	340,128	317,090	8.3
15 – 19	291,800	337,134	327,251	338,844	8.3
Total 1-19	1,216,682	1,273,348	1,234,806	1,231,708[1]	32.1
Total Population	2,716,000	3,203,956	3,527,766	3,833,482	

1. This figure does not include infants 0 to 1 years.

According to the last Census (1990), 66% of our children lived below the poverty level as compared to 21% in the mainland.

Morbidity

During the first half of the 20th century, infectious diseases were the primary threat to child health. The first causes of death were pneumonia, gastroenteritis, meningitis, parasitosis, malnutrition and vaccine-preventable illnesses. However, with the advent of antibiotics, immunizations and other effective medical interventions, mortality and morbidity from infections declined markedly. As we enter the first decade of the 21st century, child health problems have become more strongly related to social problems. Therefore, to address current child health problems we should focus on issues such as family structure and support, access to health and social services, prevention of injury, violence, substance abuse, chronic illnesses and mental health, among others.

Changes in Mortality During the Twentieth Century

The leading causes of death vary by age, sex and socioeconomic status. Although death rates for children in PR have dropped during the last half of the century, there is room for improvement of this health indicator.

The Health Objectives for the Year 2000 call for a reduction in the death rate for children 1-14 to 28 deaths per 100,000 and a rate of 85 per 100,000 among the 15-24 age group.

The table that follows compares the death rates in 1990 and 1998 by age groups. All age groups show a drop in the death rate, except those between 15-19 years. In this group homicides and motor vehicle crashes are the principal killers.

TABLE 12

Age Groups	Death Rates	
	1990	1998
1 – 4	46.7	32.8
5 – 9	25.6	15.6
10 – 14	20.9	20.8
15 – 19	75.5	93.6
All (1-19)	41.8	42.1

In 1998, the ten leading killers of children and adolescents 1-19 years old were: (1) homicides (29.5%), (2) all accidents (26.7%), (3) diseases of the nervous system (5.4%), (4) malignant neoplasms (5.2%), (5) suicides (5.0%), (6) diseases of the respiratory system (4.3%), (7) congenital anomalies (3.9%), (8) infectious diseases (2.1%), (9) endocrine diseases (1.9%) and (10) diseases of the digestive system (1.7%).

It is important to note that external causes of death (i.e., injuries, homicides and suicides) accounted for 61% of all deaths among children 1-19 years old. Only 39% were attributable to medical causes. All accidents were the first cause of death among the age groups 1-4, 5-9, and 10-14 years old, while homicide ranked the first place in adolescents 15-19 years old.

Morbidity

Unlike mortality data, morbidity data are more difficult to obtain. Morbidity data can be obtained by means of sample surveys. However, undiagnosed conditions will not be reported. Another problem with surveys is that subgroups with greater access to health care will often appear to have greater incidence of certain conditions.

Regarding unintentional injuries, it has been estimated that for each injury-related death, there are 40 hospitalizations, 1,120 visits to the Emergency Room and 1,600 ambulatory visits to physicians' offices.

In 1998, 138 deaths among children 1-19 years old due to unintentional injuries were registered in Puerto Rico. The estimated number of children affected by unintentional injuries is staggering. By means of the previously mentioned formula we can estimate 5,520 hospitalizations, 154,560 visits to the Emergency Room and 220,800 visits to physicians' offices. However, it is not known how many of the injured children will remain with a permanent disability.

Intentional Injuries: Child Abuse and Neglect

In spite of all our efforts aimed at preventing child abuse and neglect, the annual number of cases reported to the Department of the Family is overwhelming. During FY 1998-99, 27,713 cases of child abuse and neglect were reported in the Island. This figure represents an estimated rate of 2,250 per 100,000 children under 18 years. However, the situation may be worse, since we know that for every reported case there are three that are never disclosed.

Underlying causes for this serious health problem may be related to the significant proportion of unplanned and unwanted pregnancies, and drug abuse in the mother and partner. Frequently the abuser is not the biological father of the affected child. Also, the proportion of infants born to teenagers, most of them unmarried (81%) is another contributing factor. In Puerto Rico, 30% of these young women give birth for the 2nd to 8th time. This is an unbearable situation that contributes to child abuse and negligence, in addition to unhealthy behaviors such as alcohol consumption and drug abuse as a mean to liberate stress.

Morbidity of Preschool Age Children

Examining available data for 37,246 Head Start children enrolled in the program during FY 1999-2000 we found that the five leading health conditions were (1) dental caries, 29.6%; (2) asthma, 11.3%; (3) anemia, 9.3%; (4) obesity, 5.2%; and (5) underweight, 2.5%. It is important to underscore that four of these five conditions are related to the area of nutrition. Additionally, among all children, 13.9% were classified as CSHCN. The most common health condition of WIC participants was anemia (39%).

Morbidity of School Age Children

During FY 1999-00, there were 613,083 students enrolled in the public school system. The special education population accounted for 52,523. This figure represents 8.6% of the total population of enrolled students. In order of frequency, the most common disabilities were the following: specific learning disabilities (52%), mental retardation (25.1%), speech or language impairment (2.4%), multiple disabilities (2.4%), hearing impairment (1.6%), emotional disturbance (1.6%), orthopedic impairment (.98%), visual impairment (0.96%), autism (0.78%), deaf/blindness (0.1%) and traumatic brain injury (0.1%).

In addition to these conditions there is a large population of children with asthma, diabetes (18/100,000) and obesity. The estimated number of juvenile diabetics is close to 50,000. According to the BYRFS, 20% of the students consider themselves as obese (1997).

Health Care Access

In spite of the Medicaid cap, by July 1st, 2000, every person in Puerto Rico must have health insurance, paid either by the Government or a third party payer, or sufficient out-of-pocket money to cover medical costs. In fact, examining the type of insurance of the preschool children enrolled in the Head Start Program during 1999-2000 it was found that of 37,246 children:

69.6% had the Government Insurance Plan
10.2% had Medicaid (7.7% from San Juan)
18.3% had a third party payer
2% were without health insurance or unknown

Head Start children represent families of low socioeconomic status. Therefore, we may assume that in Puerto Rico by July 1st, 2000 over 98% of children must have either the Government Insurance Plan or a third party payer. This is an extraordinary achievement regarding the performance measure number 12.

C. <u>Adolescents</u>: In 1998, nearly 17% (655,934) of the population in PR were adolescents from 10 to 19 years, 51% were males and 49% females. This population has been increasing compared to the 1970's, and their health conditions are mainly related to psychosocial factors. Violence, including suicide, and sexual behavior, leading to unexpected pregnancy and STDs, are occurring at higher rates among adolescents.

In Puerto Rico, homicides are the first cause of death among adolescents 15–19 years, while in the USA it is accidents. Homicides have been increasing from 1991 (41.9/100,000) to 1995 (48.3/100,000). Nevertheless, in 1998 we have observed a decrease of 13.3% (41.9/100,000) in comparison to 1995. Aggressive behavior among adolescents has revealed a slight decrease. In 1995, 30% of 9th to 12th grade students reported being involved in a physical fight, decreasing to 26% in 1997 (YRBS).

Unintentional injuries (accidents) and suicides occupy the second and third positions, respectively, among the five leading causes of death among adolescents 15–19. Accidents revealed a 17.7% increase since 1995, from 26.5/100,000 to 32.3/100,000 in 1998. Motor vehicle crashes represent almost 70% of all accidents. During 1995 and 1996, motor vehicle crash deaths in youths 15–24 maintained an average rate of 21/100,000, compared with 32.3/100,000 in 1998.

Suicide among adolescents 15 to 19 year old has been increasing since 1995, from 3/100,000, to 7/100,000 in 1998 (preliminary data, Vital Statistics). As revealed by the YRBS, in 1991, 7.4% of students reported they had attempted suicide, 20% had seriously thought of suicide and 12% had planned. In 1997, nearly 15.6% of students had seriously thought of suicide, while 13% had planned and 11% had attempted to commit the act.

Tobacco use is the gateway for other negative behaviors. If we compare data from 1997 (Consulta Juvenil IV) with that of 1994, students from all grade levels in PR, reported an increased use of tobacco, except those from junior high school who maintained a level of 24%. The proportion of elementary grade students using tobacco increased from 7% to 9% and the high school students from 39% to 43%. As reported by YRBS, students who reported tobacco use during the last month registered 19% in 1997, compared to 18.7% in 1995.

Adolescent sexual activity, unwelcome pregnancy and out of wedlock childbirth, especially among younger adolescents, have escalated dramatically during the past decade. Puerto Rico has been facing an increasing trend in the proportion of live births to adolescent mothers (from 17% in 1988 to 20. 4% in 1998). A slight decrease has been observed between 1997 (20.7%) to 1998 (20.4%). Currently, infant mortality (13.3 per 1,000) and low birth weight (13.2%) among adolescent mothers surpass values for non-adolescent mothers (20 years or more). During 1998, only 70% of adolescents received prenatal care during the first trimester, compared to 81% of women 20 years and older.

While in the USA the birth rate to adolescent mothers 15–19 years old has been decreasing since 1991, in PR it has maintained a steady and elevated position, representing 73/1000 during 1991 and 76.5 in 1997. When comparing birth rates to adolescents 15-17 during the same period, an increase of 8.4% can be noted, from 51/1,000 to 55.7/1,000, respectively. During 1996, PR ranked third among all states and territories of the nation with the highest birth rates in this age group (15–17). It puts those mothers at higher risk due to the biopsychosocial effects of pregnancy in the mother, the father and the baby. As revealed by the YRBS, there has been a decrease in the proportion of adolescents who have had sexual intercourse at some time in their lives, from 36% in 1995 to 31% in 1997 (YRBS). However, the proportion of sexually active adolescents who used condoms decreased from 40.3% in 1995 to only 34% in 1997. Teens begin having sex at younger ages (14 years) than in the USA (16 years). Most of the adolescents (46%) with sexual experience reported sexual debut at age 14 or less (Consulta Juvenil II). It is important to note this fact, since it has been suggested that adolescents get pregnant during the first six month of sexual intercourse and that the earlier the first sexual experience, the greater the risk of contracting a sexually transmitted disease. The presence of a sexually transmitted disease increases the likelihood of HIV infection.

Chlamydia is the most common sexually transmitted disease among adolescents. Of all confirmed cases reported in PR during 1997 and 1998, females 15 to 19 years represent 38% and 36%, respectively. These values are equivalent to a rate of 4.8 cases per 1,000 females in 1997 and 3.6 cases per 1,000 in 1998. In our visits to schools, we have observed that many adolescents don't even know the name of this disease. Nevertheless, the situation is quite different regarding HIV; almost 89% of adolescents report they have been informed about HIV in school. Although adolescents (13 to 19) constitute 0.5% of all AIDS cases in PR, young adults (age 20–29) constitute 19%. It is conceivable to think that many of these young adults were infected with the human immunodeficiency virus (HIV) during adolescence, since the median incubation period is ten years. Research done in PR during 1994 (HIV/AIDS Risk Factors among Adolescents in PR, 1994) revealed that almost 28% of students have engaged in sexual intercourse, most of them had their first sexual experience before age 14 (median), 44.5% used a condom during their last sexual activity as the most-used contraceptive method followed by withdrawal (13.8%) and pills (5.4%). Only 27.6% always used condoms.

Alcohol is the drug most commonly used by adolescents in Puerto Rico. Alcohol and drug use have been shown to have a strong effect on the time of sexual debut, are strongly related to teen pregnancy and have been shown to be the best predictors of sexual risk behaviors for

STDs and HIV infection among high school students. Alcohol use among adolescents 15–18 showed a significant increase in 1997 (63%), compared to 1991 (38%) (YRBS). Those values are similar to findings from public and private junior high schools, in which there is a prevalence of 58% compared to 85% in high school level (1997–1998 Consulta Juvenil IV). Comparing 1994 data with that of 1997, a substantial decrease in alcohol use among students from elementary (45% to 34%) and junior high school level (65% to 58%) was revealed. Nevertheless, students from high school level maintained the same rate (85%) in those years (Consulta Juvenil IV).

According to the information described earlier, we can conclude that drug use, violent (including suicide) and sexual behaviors are real health problems leading to a negative impact on the health status of Puerto Rican adolescents.

D. <u>CSHCN</u> – As of 1998, the estimated population of people living in PR under 19 years of age was 1,292,226. Using the 5.5% approach to estimate the number of children with developmental delay and/or disabilities, we can say that approximately 71,072 CSHCN live in PR. The sociodemographic and risk factors described for the population of mothers, children and adolescents apply to the population of CSHCN.

By July 2000, 98% of the population in PR is expected to have the GIP, which provides a comprehensive package of services for the special population including primary, preventive and rehabilitative services. However, for the special population, the increased availability of services doesn't necessarily imply access to needed services. Our special population has no SSI benefits and the Medicaid cap limits services such as durable medical equipment and assistive technology devices to be available as needed.

As a strength of the system we can mention that for the past two years great achievements have taken place regarding collaboration between ASES and the insurance companies which are expected to result in an increased access to services. Collaboration with Medicaid is one of the outcomes described in the Annual Report.

Preliminary data recently obtained by Medicaid revealed that out of 558,259 children 0 to 21 years of age that are certified as eligible for the GIP in the 0-200% of poverty level, 2,103 were CSHCN. Seventy-two percent (72%) of the total were among the 0-100% poverty level. Further analysis may provide data on prevalence of conditions per municipalities, a useful tool for coordination of services with the Pediatric Centers.

For the total of CSHCN identified, asthma was the most common diagnosis (48%), followed by congenital anomalies (6%), mental disorders (7%), mental retardation (5%), musculoskeletal and hereditary disorders (4%), diabetes mellitus (4%) and developmental delays (3%). Seventy-eight percent (78%) of the conditions were reported among the 1-14 years age group (**Figure 18**).

Another source of information available to the MCH population is the Basic Sample Survey under revision to include a larger population and the data relevant to the core programs. The Basic Sample Survey is an annual stratified probabilistic survey of 3,000 personal interviews based on the guides established by the National Health Interview Survey of the National Center for Health Statistics. For FY 1994, the sample included 4,246 persons, showing that 47.4% were male and 52.6% female. The rate for disabilities due to chronic diseases was 37.9/100 persons, with female predominance. Sample survey results based on estimates revealed that apparently every person have some kind of disability irrespective of the etiology. Congenital conditions were more frequent in men (5.6/100) as compared to women (4.15/100). Sixty-five percent (65%) of disabilities due to deformities in extremities, back and trunk were secondary to congenital malformations. Eighty (80%) percent reported that the condition was a result of a disease.

Other data on the number of chronic conditions by cause or impairment revealed that 79% were of congenital etiology in the population 0-5 years old. Among these age group speech and language and mental disorders were the most prevalent. For the 6-16 years age group 46% of the conditions were congenital, 11.8% due to some disease and 10.6% to lesion. It is relevant about these data that hearing problems due to illnesses represents a rate of 67.6/100 persons. These data may be used as a baseline to be compared with data obtained through other activities for age groups under Title V.

Cardiovascular disorders rank number one among the causes of death in PR, followed by cancer, diabetes mellitus and cerebrovascular accidents. The mortality rate for diabetes has gradually increase. As will be discussed further on there is a high prevalence of DM in children living in PR as compared to other ethnic groups in US.

In the recent year bronchial asthma, and apparent long standing health problem, has been identified as a serious health care concern that needs to be urgently addressed. Bronchial asthma is the most prevalent of the chronic conditions in childhood in PR. A greater prevalence is observed in the 0-5 years old age group. Data collected by the MCH Program in PR during the past years revealed asthma to be the most frequent cause of admissions of children to the intensive care units. Puerto Rico has three times the US mortality rate due to this condition; reason why PR decided to include a SPM intended to reduce mortality due to asthma in children 0-14 years of age. Various studies performed in the island have revealed a prevalence of 15% with an accumulated prevalence of 35%. Epidemiological studies done in the Cataño Basin and compared to results in Loíza, municipality that is not considered a highly polluted region, revealed similar prevalence. Other etiologic factors such as genetic and environmental triggers need to be explored in more detail.

To address the above-identified issues, in 1998 an initiative was started by the PR Department of Health and the Pulmonary Section of the University of PR School of Medicine to develop an Asthma Coalition using a multidisciplinary, collaborative model. The objective of this alliance was to educate the child, family and the primary providers on how to manage the condition according to established standards of care. The coalition is composed of various

stakeholders including the DOH, Triple C insurance company, Glaxo-Wellcome, the Cardiovascular Hospital, the Pulmonary Group of the University of PR School of Medicine, ASES, parents and the Ponce School of Medicine. Studies performed by pharmaceutical companies as well as by insurance companies in PR revealed inappropriate use of medications by physicians and minimal use of anti-inflammatory agents as recommended in the NIH Guidelines.

A total of 100 families have already participated in the Asthma program since September 1999. Services are provided by a multidisciplinary team including pneumologists, registered nurse, health educator, nutritionist, secretary and respiratory therapy technician. Moderate to severe asthmatic children are referred by the primary physician and sent back with recommendations for follow up management. Studies performed to evaluate the results of the program include a decrease in the number of hospitalizations and the emergency room visits, use of appropriate medications, increase in general well being and quality of life and better knowledge of the condition, revealed general improvement in all parameters
(**Figures 19, 20 & 21**).

During FY 1999, data obtained from ASES revealed a total of 1,586 hospitalizations due to Bronchial Asthma in children less than five years of age. Out of these group the largest percentage is 24% in children less than 1 year of age. This tendency is also seen in the US for this age group. Data from some private and privatized hospitals around the island was collected this year for the first time. PR will celebrate its First Asthma Forum next October 2000 to share asthma issues and to discuss our work action plan.

PR reviewed its established eligibility criteria for admission to Pediatric Centers in view of the benefit package under the GIP. Eligibility is based on diagnostic categories that include spina bifida, cerebral palsy, cleft lip and palate, orthopedic conditions, mental retardation and hearing and speech disorders, among the most frequent conditions.

It is estimated that 67,743 children 0-19 years in PR are CSHCN, using the 5.5% approach. With the addition of the CHIP (Title XXI) monies, it is expected that by July 2000 all the Medicaid-eligible CSHCN population will be enrolled. CSHCN now have access to a comprehensive benefit package including rehabilitation services.

There is scarcity of neurosurgeons and pediatric neurologists throughout the Island, these services are mostly located in the Metropolitan Area. The Pediatric Centers are fostering contracts for subspecialty professionals for services under the GIP package. The same is true for subspecialists serving cleft lip and palate conditions where services are fragmented. With the addition of this condition to our Birth Registry and the recent revision of the protocol to include new modalities of treatment expected to expand services to this population offering coordinated, multidisciplinary services with the GIP.
Public and private sectors established collaborative processes to assure delivery of comprehensive services to CSHCN population. Concentrated efforts with Medicaid resulted in an increased number of children identified in a database and enrolled in the GIP. The

Health Care Reform provided for an increase in the number of providers needed for the varied needs of the medical conditions identified. Children may be referred to the Pediatric Centers for specialized services. Procedures are in place through ASES so that referrals are not needed from the primary care providers except for the initial visit to the center. This benefit has been recently extended to the severe asthmatic population through the Asthma program.

During this year significant changes were implemented in the MA-2 form for the Medicaid Information System, which will make possible gathering information on medical conditions of CSHCN. The MA-2 form is used annually for the certification of our population for the GIP.

The CSHCN's medical conditions identified for the Medicaid certification were grouped as follows: 1) Metabolic Disorders; 2) Hereditary Disorders; 3) Musculoskeletal Disorders; 4) Congenital Anomalies; 5) Disorders related to Sensory Organs; 6) Burns and Trauma; 7) Developmental Delays; 8) Bronchial Asthma; 9) Mental Disorders; 10) Mental Retardation; 11) Juvenile Diabetes Mellitus; 12) Hematological Disorders; 13) Cancer; and 14) Others.

This revised format will also allow for the identification of the sources of medical insurance including CHIP, in addition to those not eligible for the HCR. This initiative creates the first comprehensive up to date data source for the prevalence of CSHCN served under the GIP in PR. This information constitutes a valuable tool for future negotiations with the insurance companies and to perform risk adjustment analyses targeted to improved models of systems of care for this population.

The collected information will also contribute to the denominator for the NPM#3 regarding medical homes for CSHCN. It will provide an alternative to the SLAITS, a centrally administered telephone survey mechanism not available to PR.

Another area of rapid growth responding to families request are the genetic services. These services have been extended throughout the island and are now available in Mayagüez, Ponce, Bayamón, Caguas and Arecibo, in addition to the Metropolitan Area. Parents of children with metabolic disorders have formed active and strong support groups in the western region and are also participating in the SSDI Regional Working Group. Genetic literature in Spanish for families and the medical community has been developed. Linkages between professionals, advocacy groups and the public health system have thus been strengthened. Educational conferences have taken place islandwide to benefit primary care physicians.

The Birth Defects Registry was expanded last year to include Cleft lip/palate. The reported incidence for FY 1999 was 0.7/1,000 live births. A multidisciplinary team located at the Metropolitan Pediatric Center provides services to children with this condition. Linkage with the EIP is facilitated through coordination established by the Pediatric Centers with the birthing hospitals (**Figure 22 & 23**).

APNI, the Association of Parents of Children with Disabilities has been providing orientation and advocacy for children and families for several years. Updated information including new

legislation, programs issues and concerns are published every six months in their bulletin. A family advocacy member was appointed to APNI in order to work closely with the Title V Central staff to strengthen parent groups at the Pediatric Centers and at regional levels. The father of a child who attended the EIP was recently appointed as Puerto Rico's representative for Family Voices and for the Federal Coordinating Council of the EIP.

3.1.2.2 Direct Health Care Services

1. Preventive and primary care for pregnant women, mothers and infants: Preventive services for this sub-group of the MCH population are well covered through the Government Insurance Plan and supplemented by Title V and other federal and state supported programs. The number of WCBA with the GIP is 368,659 (15-44 years). Indeed, no co-payment is permitted in providing primary services to pregnant women and infant care. As of December 1999, the number of infants, children and adolescents (0-19 years) holding the GIP amounted 641,695.

Family planning methods are supplemented with Title V funds. In addition, Title X and PROFAMILIA, a community based organization that is supported by state funds, provide family planning services to a segment of the population. The pediatric AIDS program, in coordination with the Title V program, supports counseling, testing and treatment with AZT on a voluntary basis to all pregnant women and infants found HIV positive. The newborn screening for hereditary diseases is supported by state funds. Currently, over 98% of all children in PR should have either the GIP or a third-party payer health insurance.

2. Preventive and primary care services for children: The primary and preventive services for this sub-group are also covered by the Government Insurance Plan. The scope of services includes screening, diagnosis and treatment for identified conditions, referrals to specialists, dental services (including sealants) that can be accessed directly, and immunizations supported by federal and state funds.

3. CSHCN

CSHCN have access to preventive and primary care services through the Government Insurance Plan (GIP). The scope of primary services includes evaluation, diagnosis and treatment, emergency services, x rays, laboratories, genetic services, urine and blood screening tests for metabolic disorders, rehabilitation services including physical, occupational and speech therapies, dental services and immunizations. Services not covered under the benefits of the plan are provided through Title V funds; these include psychosocial services, service coordination, orthoses, assistive equipment such as hearing aids and eyeglasses for selected conditions, braces, special formulas for children over 5 years of age with metabolic disorders and some medications.

The Pediatric Center staff which are skilled and trained in the required procedures for various conditions, including children with multiple congenital anomalies, provide specialized medical services. Physical therapies exceeding the number covered by the GIP are provided with Title V funds. Pediatric Centers are providers of specialized services to CSHCN for the HCR; insurance companies reimburse the Department of Health for services under coverage by the GIP. The

skilled professionals of various subspecialties at the Pediatric Centers complement the reduced number of these professionals available islandwide through the GIP.

During the last four years an average of 10,321 children have been served at the seven Pediatric Centers located strategically throughout the island, one in each health region. Patients served per population in each region for FY 1998 are:

Pediatric Center	Total Patients Served
Metropolitan	2,343
Ponce	2,117
Caguas	1,974
Arecibo	1,125
Mayagüez	1,063
Bayamón	948
Fajardo	457
Total	10,027

This total represents 14.8% of the estimated population of CSHCN in the Island. The total number of children served decreased from 10,871 in 1996-97 to 10,065 in 1997-98 with no significant change observed for 1998-99 (10,027).

A significant accomplishment of the system of services to CSHCN is that for the first time since the implementation of the HCR, the Division of Habilitative Services have data from the insurance companies under ASES regarding the number of CSHCN and the number of children identified per diagnosis per region. According to the data reported by ASES for FY 1998-99 the total number of participants of the GIP were 1,700,666; of these 641,695 were between 0-19 years of age. Data reported by ASES for 1999 revealed a total of 4,237 CSHCN. The most common diagnoses in order of frequency are: 1) Musculoskeletal conditions (46%); 2) Congenital anomalies (18%); 3) Conditions related to sensory organs (15%); 4) Hereditary disorders (14%); 5) Metabolic disorders (5%); 6) Burns (1%); and 7) Others (1%).

*Asthma was not initially in the list of conditions for this reporting year.

The central region had the highest number of patients followed by the northern and eastern regions; the lowest was the southwest region. Data for the municipality of San Juan, the capital city, is not included since it entered the HCR in July 2000. The number of children with musculoskeletal conditions is very high in the northern area as the hereditary conditions in the central regions of the Island, where consanguineous marriage is very common. The collaboration established between the MCH/CSHCN, ASES and the insurance companies have made possible for PR to present data for the first time on the conditions affecting the special needs population and their geographical distribution. This is a valuable information in order to negotiate alternate models of services with the insurance companies. It also provides for the distribution of funds according to identified needs.

We have also made some efforts to gather data on services to this population in the private sectors. Data collected from six community providers islandwide revealed that 902 children were

served during 1999. The most common diagnoses are: speech disorders, Down Syndrome, cerebral palsy, psychomotor retardation and learning disorders.

The Department of Education served 52,523 children within the 3-21 years of age range as of December 1999; specific learning disabilities (52%), followed by mental retardation (25%) and speech and language impairments (12%), were the three most common conditions. The number of children served through the special education program showed a considerable increase of 13% during the last two years. This significant increase may represent increased efforts by DOH in the identification of children with developmental delay, more effective transition procedures from Part C to Part B with an increase in the number of children served by DOE.

A survey of parents and Pediatric Centers staff performed in 1997 by Estudios Técnicos, Inc., as part of a needs assessment study, revealed that the most frequent conditions presented by our clientele are Down Syndrome (58%), motor retardation (54%), speech and language problems (50%), cerebral palsy (45%) and spina bifida (41%).

Head Start children numbered 37,246 according to FY 1999 data, 14% of there were CSHCN. Among Head Start participants, 69.6% had GIP, 18.3% had private insurance, 10.2% had Medicaid and 2% with no insurance. The most common conditions in order of frequency were: dental caries (30%), asthma (11.3%), anemia (9.3%) and obesity (5%). Other conditions related to CSHCN were: speech and language problems (0.2%), diabetes mellitus (0.12%), visual problems (0.04%), sickle cell (0.03%) and hearing problems (0.026%).

Diabetes Mellitus ranks third among the leading causes of death in PR. PR is participating in the World Health Organizations (WHO's) Diamond Project of Insulin Dependent Diabetes Mellitus (IDDM) incidence, genetic and outcome that involves more than 120 centers in 69 countries and includes 5% of children with IDDM in the world. Beginning in 1990, new cases of IDDM were registered retrospectively from 1985 and prospectively to 1994 by review of medical records from hospitals in the Island. Included in the hospital registry are 1,527 cases of IDDM. Epidemiological investigations in Spanish heritage populations in the Americas are potential sources to quantitate the effects of genetic admixture, socioeconomic conditions and geography in IDDM.

A study performed in PR by the Ponce School of Medicine and the Pediatric University Hospital and published in 1997, "Incidence of Insulin Dependent Diabetes Mellitus in Children living in PR" (data collected through the infrastructure of the WHO) revealed a mean incidence from 1985 to 1994 of 18 cases/100,000 children less than15 years of age per year, with a slight female (51%) to male (49%) predominance. According to the investigators, these results indicate that the annual incidence of Diabetes Mellitus in children living in PR is higher than the incidence for other multiracial ethnic groups living in the US.

3.1.2.3 Enabling Services

1. Pregnant women, women and infants: Enabling services for this group include home visiting services for at-risk pregnant women and infants, outreach, post-partum education and referrals to

the WIC and other programs. As of December 1999, the MCH program had 103 home visiting nurses, and 85 outreachers in Reform areas.

2. Children: Home visiting services are also provided for children up to age 3, outreach services and WIC up to 5 years of age. Childcare, when needed, is coordinated at the local level with available resources, which include extended family, community groups and referrals to the Department of the Family.

The implementation of the HCR in PR has markedly reduced financial barriers to primary/preventive care and specialty/sub-specialty care, and improved accessibility to habilitation and rehabilitation services for all MCH population groups. As mentioned elsewhere, one of the goals of the HCR is to assure needed health services to all residents in PR, irrespective of their ability to pay.

The shift in Medicaid coverage over the last five years has not affected PR. Historically, PR had provided health care services mainly with state funds due to the Medicaid cap imposed on the Island.

Puerto Rico has moved faster than other states in the implementation of managed care delivery models. This change in the service delivery system has markedly increased the accessibility of health care resources for the MCH population.

Regarding the impact of the Welfare Reform on the MCH population, including SSI population, we expect no negative changes because we do not receive SSI funds. The only requirement for receiving the GIP is to be under 200% poverty line.

As described elsewhere, the HCR has increased the availability of primary health care providers, especially pediatricians, obstetricians, dentists and home visiting nurses. Other health providers, such as nutritionists, social workers, therapists (occupational, physical, speech and language) have not increased in the same proportion. However, their services are more accessible through referrals by primary providers.

The implementation of the HCR does not affect the regionalized health care delivery system in Puerto Rico. The network of primary providers of insurance companies may refer their patients to any level of service, as deemed necessary.

In addition, the home visiting nurses and outreach workers who belong to the MCH program are the best resource at the community level for linking the vulnerable MCH population to the different levels of care as well as to other human services.

3. CSHCN

As mentioned earlier, the GIP has definitely improved access to preventive and primary services providing choices for families and expanding the number of providers for a variety of services. In fact, this Medicaid shift provides an opportunity to rethink towards more effective and efficient

models of service delivery for this population. The money reimbursed by insurance companies can be reinvested in unmet needs of this population.

A satisfaction study on the Health Care Reform done in FY 1998-99 by Estudios Técnicos, Inc. revealed over 90% satisfaction for the general population of enrollees in various parameters. The implementation of the HCR in PR has markedly reduced financial barriers to primary and preventive care as well as to habilitative and rehabilitative services. Referrals to specialists are still an area of concern for families of CSHCN as manifested by families generally in managed care settings nationwide as well. However, in the case of PR the Medicaid cap constitutes a barrier since the capitation rate for physicians is low if compared to those of the US. Services package of the HCR has been recognized as one of the most comprehensive in the MCO market.

Welfare Reform for families with CSHCN in PR may have probably caused similar effects as in the US, no matter that our population doesn't have SSI benefits. The Child Care Program under the Department of the Family has been more active in public awareness activities to promote priority for services to CSHCN up to 18 years of age, whose parents are working or studying. The Director of the CSHCN program is the representative of the DOH at initiatives underway in PR geared to the implementation of the Work Incentive Act.

By July 2000, with the implementation of the GIP in San Juan it is expected that 98% of the total population will have medical insurance: 42.2% GIP, 44.1% private, 13.5% Medicaid, only 2.8% will have no insurance. CHIP monies definitely contributed so that approximately 150,000 children 0-21 years of age were enrolled in the GIP according to Medicaid data as of June 2000.

The CSHCN Program has been establishing coordination with the educational task force of the insurance companies and ASES so that primary providers understand the linkage with Title V and its responsibility in assuring appropriate and quality services for this vulnerable population. Advantages of providing early and appropriate services are promoted as a means of developing a cost effective system. Triple C participated in the revision of the list of conditions for CSHCN in PR. The revised list was used to modify the MA-2 Medicaid form, and is shared with the insurance companies, as a way to assist the primary physician in the identification of the special population. The participation of PR in the Tri-Regional Meeting held in Baltimore in 1999 provided an excellent opportunity to gather key stakeholders who have kept together working and looking to improve our system to better serve this population.

The Division has also been involved in training selected Pediatric Center staff in culturally competent models of services to this population. The staff is provided in service training following a need assessment.

Strategies have been designed to facilitate access of CSHCN to the services provided at the Pediatric Center. Among them, referral notes to specialists by the primary provider are not required after the first visit to the center. Another strategy is to improve the coordination with primary providers so that CSHCN can access rehabilitation services included in the GIP. The CSHCN program has recruited subspecialists to increase availability of special services. Access

to related services such as physical, occupational and speech therapies, audiological, psychological and nutritional services will be improved by the certification of providers from Pediatric Centers as providers of these services for the GIP.

Results of a need assessment study performed by Estudios Técnicos, Inc. in 1997 included: 1) Scarcity of allied health professionals mostly outside of the Metropolitan Area; 2) Need of better knowledge by the physicians on diagnoses of CSHCN and of more time to talk with families about the child's prognosis and implications for quality of life; 3) Physicians need to be more sensitive to families' issues and concerns; and 4) Scarce subspecialties in regions outside of Metropolitan Area, such as orthopedic, neurosurgery and neurology.

During year 2000, SSDI and the Division of Habilitative services joined efforts to run parents' focus groups at the Pediatric Centers in Arecibo, Ponce, Metropolitan Area and Bayamón. Among the main concerns were: 1) Reluctance of primary physicians to give referrals for subspecialists. 2) Scarcity of subspecialists outside of the Metropolitan Area. 3) Parents do not receive adequate information from primary physicians regarding children's conditions. 4) Related services for children 0-21 are scarse. 5) The need for a service coordinator for the 0-21 population. 6) Need for support services for families in order to access subspecialized services.

Puerto Rico has a wealth of health care resources well distributed across the Island. For some of the subspecialized services they are centralized in the Metropolitan region. The Pediatric Centers have an inter-referral process in place for such services. The Pediatric University Hospital is not under consideration for privatization and remains as a safety pouch for our special population. Under Administrative Law #95 the Metropolitan Pediatric Center is administratively affiliated to the Pediatric University Hospital, providing access to variety of subspecialists and other services available at the Pediatric University Hospital, such as cardiology, endocrinology and hematology, among others. A variety of subspecialists and allied health professionals are available at the Pediatric Centers. The total distribution of subspecialists and allied health professionals for GIP and Pediatric Centers is also shown. These providers are financed through a combination of Title V, state and other federal funds (**Figures 24 & 25**).

The decision made by our Secretary of Health at the beginning of the HCR to continue providing specialized services to this vulnerable population at the DOH Pediatric Centers proved to be a very wise one. Due to the conservative capitation rates in the Island some primary providers and subspecialists are not willing to dedicate the time that our families and children require and deserve. The Pediatric Centers actually complement medical subspecialty and other services for the CSHCN. The Service Coordination component to be added soon to our services list will definitely address many of our families' concerns and unmet needs.

3.1.2.4 Population-Based Services

1. Pregnant women, women and infants: There are several programs aimed at the population at large which include newborn screening for phenylketonuria, hypothyroidism, sickle cell and

Galactosemia; immunizations; neural tube defects prevention; toll free line; screening for developmental delay; postpartum education and public education.

2. Children and adolescents: Several programs address the needs of children and adolescents. Among these are the following: the immunization program, the toll free line, the abstinence education program, public education, injury prevention and the Comprehensive Adolescent Health Program.

Most of the population-based services are coordinated with other programs, agencies and managed care organizations. A combination of state and federal funds is used to support the population-based programs previously mentioned.

3. CSHCN: Population based services have been an area of great improvement for this population. Infants confirmed as positive by the neonatal screening program are now referred to the primary physician through the GIP and to the nearest Pediatric Center of Habilitative Services for the provision and/or coordination of other needed services. For children with PKU or other metabolic disorders over 5 years of age who still require special nutrition formulas and/or nutrition evaluation and follow up, these are provided at the Pediatric Centers. A geneticist has been recruited to enhance services which are provided at the Pediatric Centers in Mayagüez, Ponce, Caguas and Arecibo.

Meetings with representatives of the insurance companies of the GIP have taken place for further dissemination of services provided at Pediatric Centers, as a means of collaboration with the islandwide network of primary providers. Information is periodically disseminated to families of CSHCN through the Parent Information Center or managed care bulletins. As an example of such collaboration, agreements are under way with insurance agencies under GIP to improve access to services through the recently established Asthma Program at the Cardiovascular Hospital.

Folic acid campaign efforts for the reduction of NTD are continuous. Train-the-trainer annual update activities addressing the 10-50 years of age at-risk women in Puerto Rico were completed with the participation of previously trained professionals and Pediatric Centers' Medical Directors. Additional educational efforts are needed to increase the number of women who once being informed take the folic acid tablet daily as required.

Joint efforts with the Department of Education included: (1) further development of the school health curriculum for junior and high school students to include the folic acid campaign; (2) training of adolescent facilitators at public schools; (3) planning for inclusion of folic acid rich foods in the school lunch programs; and (4) elaboration of an instructional module for the elementary school.

The Folic Acid Campaign evaluation phase in 1997 included the distribution of 9,000 questionnaires on folic acid knowledge and use to at-risk women in seven (7) agencies. The results showed improvement for recommending folic acid intake daily, but those women used very little supplementation. The Puerto Rico Department of Health NTD surveillance system

resulting from the folic acid campaign corroborated the suspected very high incidence of NTD in PR, 1.6 NTD's /1,000 live births for the 1996. There were 100 affected pregnancies that year in Puerto Rico. Data for 1999 revealed an incidence rate of 0.8/1,000 live births, a 50% decrease in trend as compared to initial data of the surveillance system.

Other dissemination activities have been coordinated with the Council for Developmental Disabilities through radio and television, as well as by the Office of the Ombudsman for Persons with Disabilities.

The Department of Health has also completed training for the Pediatric Center staff and GIP primary providers in the prevention of recurrences of NTD's. Stronger linkages are needed to include primary physicians and obstetricians in the follow up of mothers with history of a previous baby with NTD's and the daily supplementation with 4 mg of folic acid in planning for another pregnancy and during the first three months of pregnancy.

On June 7, 1996, Educational Law #51 replaced the existing Law #21 regarding special education. As one of DOH's responsibilities, all babies born in a DOH or privatized facility shall be screened for developmental delay during the first three months of age and, with parental consent, referred to one of the Pediatric Centers for evaluation, eligibility determination and provision of services available under Part C, Infants and Toddlers Program. The final regulations by the Department of Education are not yet in place, so the full impact of this law is yet to be experienced**.** Meanwhile, efforts have been directed toward educating physicians Islandwide in coordination with UAP and the Parents' Information Center. The EIP has definitely contributed to the increase in the number of children enrolled in preschool services observed during the past two years.

3.1.2.5 Infrastructure Building Services

The coordination mechanisms that support the infrastructure building services for the MCH/CSHCN populations have been previously described in section 1.5.2. In addition, the wide array of infrastructure building services is contained in the MCH pyramid of the core public health services (see **Figure 10**).

The guidelines developed for follow-up of CSHCN will be disseminated through ASES and the health insurance companies to the network of primary providers. Both ASES and the insurance companies have developed and established evaluation protocols to assure that services are being provided according to current standards of care.

Developing a community based service system for the MCH program during these times of transition, from a traditional system to the new evolving system of managed care, is a priority. Towards this goal, a state interagency committee and eight regional working groups (RWG's) have been established. The Division of Habilitative Services will continue fostering family participation at regional levels in order to strengthen community based systems of services.

The MCH Regional Director, in coordination with the state level SSDI coordinator, leads the RWG's. These RWG's meet on a regular basis to assess the MCH needs, including CSHCN, and to provide recommendations to better serve the target population. To improve the skills of the RWG's in performing their tasks, they were provided with a three-day seminar. The seminar covered a wide array of topics concerning systems development, needs assessment and coordination. The comments received from the participants were very encouraging. A total of 165 professionals and consumers were reached with this activity.

The MCH/CSHCN Programs have worked collaboratively to promote the need for comprehensive systems of services especially important in the managed care environment. The CSHCN program has worked closely with ASES, Medicaid and the insurance companies in the identification of CSHCN, which has provided baseline data to start thinking on improving and/or creating alternate models of care to better serve this population. Strong collaborations have taken place with the DOE for the folic acid campaign, the Abstinence Education program and for transition agreements from EIP to preschool. Combined efforts with Child Care, Head Start and Early Head Start programs will also assist in the identification of the population and in establishing linkages for a continuum of services across systems. Technical assistance through the University Affiliated Program of the School of Public Health has provided the opportunity to visualize training of personnel for early childhood, combining efforts from various public and private agencies involved with the population 0-8 years of age. The Coalition for Asthma is expected to cross frontiers in an effort to gather data from several sources islandwide and at the same time for other medical conditions and initiatives such as the newborn hearing screening program.

The CSHCN Program has participated with the Mental Retardation Program in various activities at national and local levels geared towards the desinstitutionalization of this population and the integration to the community. Various participants of the residential program under DOH have already transitioned successfully into the communities. The EIP, in collaboration with APNI, empowers families to serve as advocates for the children as they undergo their various transitions across the system.

As mentioned earlier the GIP has markedly improved access to services in PR; it has also alerted the core programs under the Auxiliary Secretariat for Prevention and Promotion about the importance of moving towards providing services not under the GIP coverage and establishing mechanisms for the provision of coordinated services. The Title V Case Coordinator is expected to address unmet needs by establishing coordination with DOE, Department of the Family, Vocational Rehabilitation and the Office of the Ombudsman for Persons with Disabilities.

In summary, with the implementation of the HCR, PR has made a wide array of primary providers and services accessible for CSHCN and families. Education to the general public through public awareness strategies to reduce incidence of chronic disabling conditions and to prevent further complications constitutes a big challenge. Continued education to physicians and allied professionals regarding standards of care and specifically in the cost effectiveness of provision of coordinated, family centered services is a priority. New strategies geared towards changing

attitudes and behaviors need to be incorporated. Technical assistance regarding data collection, system linkages and collaboration between federal programs will definitely assist PR in this endeavor.

3.2 Health Status Indicators

This five years needs assessment has charged states and jurisdictions with 23 new health indicators: 8 core, 5 sociodemographic and 10 developmental. The collection of data needed to assess a significant number of these indicators is not under the responsibility of the Title V agency. Therefore, Title V must identify the source of data needed and the program or agency that would collect it and develop the mechanisms to gather the data as required by each health indicator. In our case, we found that even though some data are collected, it does not satisfy the requirements for some the health indicators. Most of the time it is fragmented and collected in different ways, so it is difficult to compare. This is a problem that will be repeated if HRSA/MCHB does not establish at the federal level standards, guidelines and requirement for collecting data by the different programs supported by federal monies. Toward this aim we recommend that every federally supported program must share their data with other federal programs as requested.

All efforts were done to gather required data for each indicator. However, we were unsuccessful in acquiring reliable data for several of the health status indicators. The MCH/CSHCN programs will continue its efforts to improve the data base system. Towards this goal a Data Utilization and Evaluation Project proposal was recently submitted to the MCHB.

3.2.1 Priority Needs

1. To reduce infant, child and maternal morbidity and mortality.
2. To increase availability and access to preventive and primary health care services for the MCH population, including CSHCN.
3. To develop and maintain an MCH infrastructure to adequately assess the health needs and to assure the delivery of appropriate and needed services for the MCH population, including CSHCN.
4. To improve collaboration among parents, public, private and community based organizations to further program coordination and integration into a system of services.
5. To reduce unwanted adolescent pregnancies.
6. To reduce unintentional injuries among children and adolescents.
7. To increase awareness regarding MCH issues among health professionals and the public at large.
8. To prevent and reduce behavioral risk factors such as smoking, alcohol consumption and substance abuse among teens and pregnant women.
9. To diminish morbidity and mortality rates due to bronchial asthma.
10. To enhance competency of the primary care providers to better serve the at-risk MCH population.

3.3 Annual Budget and Budget Justification

3.3.1 Completion of Budget Forms

Please refer to budget columns of Form 2, Form 3, Form 4 and Form 5 for FY 1998-99. Estimates had to be used in providing budget and expenditure details. Breakdown of expenditures by type of services is a very difficult task when we try to assess the performance of a public health professional. This task is quite easy at the first level of the pyramid related to direct services. At this level, we know who serves the different groups of the MCH population and the amount of time dedicated to each of the subgroups, allowing us to determine the expenditures by type of individuals served. But trying to estimate the amount of time dedicated to each of the subgroups comprising the MCH population, as well as the time dedicated to perform enabling, population-based or infrastructure building services, is not so easy. For this reason, estimates had to be made and this may lead to discrepancies between the budgeted and the expended figures. Another explanation for the discrepancies is that the process of relocating personnel in the reform area is an ongoing one, until the implementation of the HCR in Puerto Rico is completed. It is expected that in the next couple of years an equilibrium will be reached in this regard.

Justification: Program allocations have taken into account the 30-30-30-10 requirements established by Title V. Efforts are made to match funds according to the identified needs through the four levels of the MCH pyramid, as well as the three groups of individuals that comprise the target population.

Puerto Rico assures that the MCH funds are used for the purposes outlined in Title V, Section 505 of the Social Security Act. Traditionally, a fair method has been used to allocate Title V funds among individuals and geographic areas having unmet needs. As the implementation phase of the HCR reaches its final phase, the fair allocation of funds will be guided by an Integrated Index of Maternal and Infant Health Status (IIHMIS) developed by the MCH Division to assess the health needs by municipality. One of the benefits of using this Index is that the information necessary to evaluate each of its variables is available continuously through analysis of birth and death files **(Appendix 8**).

MCH funds allocated for the CSHCN program provide for services at the Pediatric Centers islandwide. The salary and benefits of the staff, professional services contracts, medication not covered by GIP, nutritional supplements and assistive technology devices like hearing aids and eyeglasses are the areas where Title V funds are distributed.

The needs identified and presented in our needs assessment support our efforts to make specialized services available through the centers. The Metropolitan Area Pediatric Center, administratively under the Pediatric University Hospital for the past four years remains a supra tertiary referral center and serves the children and families referred by the other six Pediatric Centers. The Metropolitan Area Center offers a great variety of subspecialized services to our population.

The Pediatric Centers have been billing the insurance companies for the services provided to the CSHCN under the GIP. The reimbursement process showed a considerable improvement in the amount of money collected during the year. We account for $263,000.00 available at the DOH designated account. At this stage of the process these funds will be used to strengthen the billing unit and provide for their priority needs, to cover some of the non-recurrent expenses at the Centers, to strengthen the Title V service coordinators and the information system.

As of June 2000 the Division of Habilitative services hired an accountant with an MBA to assist the director and the administrative component in all financial and budgeting related affairs. Our main concern at present is the development of an accurate pattern for the distribution of MCH funds for the seven Pediatric Centers and the central office. Some of the criteria under consideration and analysis include: the need of subspecialized services according to the prevalence of certain conditions per region considering the distance from the closest existing provider and the scarcity of some specialties throughout the island, cost of services by discipline and percent of the total CSHCN population served at the center. We expect to have a more comprehensive analysis by next year that will allow for the CSHCN program to allocate funds with a more scientific or objective approach, as previously recommended by the MCH officials.

Allocation of funds may also be projected considering alternate models of service delivery, which will be worked in collaboration with ASES and the MCO's serving the MCH/CSHCN populations.

State dollars used to provide services to the MCH population surpass by many times the requirements for the match. State funds appropriations are used for the implementation of a broad array of programs and services that contribute to improve the health and well being of the MCH populations. The table that follows presents a list of several programs supported by State dollars.

TABLE 13

Program/Service	Allocation
Government Insurance Plan[1]	$ 292,921,972
Hereditary Diseases Program	$ 200,000
Immunization Program	$ 200,000
CSHCN	$ 3,000,000
Pediatric AIDS Program	$ 1,704,970
Catastrophic Funds (CSHCN)[2]	$ 3,008,919
PROFAMILIA (Not-for-Profit Organization)	$ 220,000
Rape Crisis Center	$ 348,000
In-Kind-Administration- Space in Facilities and Utilities [3]	$300,000

1. Estimated proportion for primary preventive services. (33% of the total used [574 million] in the GIP).
2. Portion of the funds used for CSHCN only.
3. Estimated as $10.00 per square foot.

In addition to MCH dollars and the State funds previously listed, there are other federal sources of funds that contribute to the achievement of the MCH outcomes. These are included in Form #2.

Budget documentation: The Fiscal Affairs Office of the Department of Health and the Office of Federal Affairs maintain budget documentation for Title V funding and expenditures consistent with section 505(a)(1). (**Appendix 9** provides a description of the fiscal management process).

Allocations for FY 2000-2001: The estimated amount of money to run the MCH/CSHCN programs during FY 2000-01 is as follows:

Federal	:	$16,664,439.00
Unobligated (FY 1999-2000)	:	$ 1,024,310.00
State	:	$13,279,581.00
Program Income	:	$ 263,000.00
Total	**:**	**$31,231,330.00**

Allocation by MCH Population Groups:
A) $ 9,369,398 (30%): for the provision of services to pregnant women, mothers & infants.

B) $ 9,369,399 (30%): for the provision of preventive services for children.
C) $10,930,965 (35%): for the provision of services to CSHCN.
D) $ 1,561,568 (5%): for program administration.

Allocations by Levels of the Pyramid:
Direct Services: Funds will be used to purchase contraceptive methods to support the family planning services rendered through the health care reform for women holding the GIP. Even though the family planning services, including sterilization of males and females, are included in the GIP, the contraceptive methods were not included in the benefit package. Also, salaries of the 7 Pediatric Centers Staff are included in this item. The estimated amount budgeted for this level is $12,581,322.

Enabling Services: A significant amount of Title V funds is needed to support salaries of Home Visiting nurses, perinatal nurses, outreach workers, health educators, payment of mileage and for the Toll Free Information line. Funds will be allocated to San Juan through a contract between the PR Department of Health and the San Juan Department of Health. This allocation should be used to develop and implement a home visiting program and outreach activities similar to the rest of Island. The estimated amount needed for these activities is $7,913,721.

Population-Based Services: Title V monies are used to sustain the NTD prevention campaign, injury prevention, public education, purchase of educational materials and incentives that promote the toll-free line, the staff of the Comprehensive Adolescent Health Program (CAHP) and a wide array of health promotion messages. $5,144,827.

Infrastructure Building: To sustain the infrastructure of MCH/CSHCN programs, funds are used for the salaries of central and regional staff, for needs assessment and other core functions, equipment, professional development, the interactive education program, the purchase of computers and other related activities. $5,591,460.

Administration: To support salaries of administrative staff, utilities, internal audit, newspaper announcements, travel to required meetings and conferences in the mainland, office supplies, duplication of documents, mailing and others.

3.3.2 Other Requirements
Maintenance of Efforts: Puerto Rico is in compliance with maintenance of effort requirements as described in Section 505(a)(4). In fact, PR exceeded efforts of the 1989 program year. As of December 2000, there were 1,138,003 (0-44 years old) individuals with the GIP in Puerto Rico. Among these, 779,344 were infants and children including CSHCN and 358,659 were women of childbearing age (20-44 years of age). The annual cost per capita is approximately $780. Therefore, the Government of Puerto Rico invested over $887,642,340 in 1999 to pay for the health services of the MCH population. It has been estimated that about 33% ($292,921,972) of the total cost per year would be used for primary preventive services. The total budget of ASES for FY 1999-2000 is $1,001,947,000.

In addition, $3,200,000 in state funds are allocated for the CSHCN and the Hereditary Diseases program (See Table No. 11) and $3,008,919 of the Catastrophic budget were used to support 57 patients who required very expensive procedures such as liver and bone morrow transplant, heart surgery and other procedures. Most of these procedures were performed outside of PR. There are no continued special projects [Sec.505 (a)(5)(c)(I)] in the Government of Puerto Rico.

3.4 Performance Measures

3.4.1 National 'Core' Five Year Performance Measures

NPMs and State PMs are found in Form 11.

3.4.1.1 Five Year Performance Objectives

The five (5) year performance objectives are available in Form 11.

Table 14

PERFORMANCE MEASURES SUMMARY SHEET

Core Performance Measures	Pyramid Level of Service				Type of Service		
	DHC	ES	PBS	IB	C	P	RF
1) The percent of State SSI beneficiaries less than 16 years old receiving rehabilitative services from the State Children with Special Health Care Needs (CSHCN) Program.	X				X		
2) The degree to which the State Children with Special Health Care Needs (CSHCN) Program provides or pays for specialty and subspecialty services, including care coordination, not otherwise accessible or affordable to its clients.	X				X		
3) The percent of Children with Special Health Care Needs (CSHCN) in the State who have a 'medical/health home'.		X			X		
4) Percent of newborns in the State with at least one screening for each of PKU, hypothyroidism, Galactosemia, Hemoglobinopathies (e.g., the sickle cell diseases) (combined).			X				X
5) Percent of children through age 2 who have completed immunizations for Measles, Mumps, Rubella, Polio, Diphtheria, Tetanus, Pertussis, Hemophilus Influenza, Hepatitis B.			X				X
6) The birth rate (per 1,000) for teenagers aged 15 through 17 years.			X				X
7) Percent of third grade children who have received protective sealant on at least one permanent molar tooth.			X				X

Core Performance Measures	Pyramid Level of Service				Type of Service		
	DHC	ES	PBS	IB	C	P	RF
8) The rate of deaths to children aged 1-14 caused by motor vehicle crashes per 100,000 children.			X				X
9) Percentage of mothers whom breastfeed their infants at hospital discharge.			X				X
10) Percentage of newborns who have been screened for hearing impairment before hospital discharge.			X				X
11) Percent of Children with Special Health Care Needs (CSHCN) in the State CSHCN Program with a source of insurance for primary and specialty care.				X	X		
12) Percent of children without health insurance.				X	X		
13) Percent of potentially Medicaid eligible children who have received a service paid by the Medicaid Program.				X		X	
14) The degree to which the State assures family participation in program and policy activities in the State CSHCN Program.				X		X	
15) The rate (per 100,000) of suicide deaths among youths 15-19.				X			X
16) Percent of very low birth weight live births.				X			X
17) Percent of very low birth weight infants delivered at facilities for high-risk deliveries and neonates.				X			X
18) Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester.				X			X

3.4.2 State 'Negotiated' Five Year Performance Measures

3.4.2.1 Development of State Performance Measures

The table that follows summarizes the eight (8) performance measures that were developed taking into account the identified MCH health needs and priorities identified through the needs assessment and public policy established by the Secretary of Health. Discussion regarding why they were selected is found in section 3.4.2.2.

TABLE 15
DEVELOPMENT OF STATE PERFORMANCE MEASURES

Negotiated Performance Measures	Pyramid Level of Service				Type of Service			Population		
	DHC	ES	PBS	IB	C	P	RF	Mother & Infants	Children	CSHCN
1) The number of HIV positive pregnant women treated with AZT.	X				X			X		
2) Establish a home visiting program for at risk pregnant women and children under 3 years.		X			X			X		X
3) The incidence rate of NTD's.			X				X			X
4) Developing a surveillance system for selected birth defects.				X		X				X
5) Determine the prevalence of tobacco use among pregnant women.			X			X		X		
6) The birth rate among girls' 10-14 years of age.			X				X		X	
7) The rate of deaths to children aged 1-14 caused by asthma.			X				X			X
8) Developing standards of care for CSHCN.				X		X				X

NOTE: DHC = Direct Health Care ES = Enabling Services PBS = Population Based Services
IB = Infrastructure Building C = Capacity P = Process RF = Risk Factor

3.4.2.2 Discussion of State Performance Measures

Please refer to Form 7 in the Appendix section. It provides descriptions of the performance measures selected by Puerto Rico that include the type of service, the category on the pyramid, the PR goal, the measure used, how the measure is defined, the measure's relationship to H.P. 2010 if it is available, data sources, data issues and the significance of the indicator.

The selection of the state performance measures was driven by several criteria, including:

1. Each of the state performance measures intends to address a health need identified through the needs assessment conducted as requirement of the five year application for FY 2000-2001 which was not considered in the set of the 18 National Performance Measures; or if it is a requirement for the implementation of a state policy already established by the Department of Health.

2. The number of affected individuals is significant if the health need is not properly addressed and the impact on the infant and maternal mortality would be severe.

3. Whether there are services or programs under the scope of the MCH/CSHCN programs or partner programs working collaboratively on that identified health need.

4. Whether the human resources needed to develop the required activities to reach the target established for the performance measure are available.

5. Whether there is a source of quality data needed or the possibility to collect it on a regular basis to monitor the progress toward the target.

6. Whether the activities designed for each performance measure will have a collective effect to contribute to a positive impact in the accomplishment of the National and the State outcome measures.

7. In addition, other criteria used were the input gathered from regional staff, the MCH Advisory Board, SSDI Regional Working Groups and through discussion of MCH issues in interagency meetings and committees; the Agency's capacity and resources; and very important, the priorities established by the Governor to be accomplished by the Puerto Rico Department of Health.

3.4.2.3 Five Year Performance Objectives

Please refer to Form 11, PR State Performance Measures: 01 to 08.

3.4.2.4 Review of State Performance Measures

The review and negotiation of State performance measures will be performed by the MCHB and Region II MCH staff, discussed and negotiated with local staff during the face-to-face application and annual report review session. For PR, this activity will be held on August 16, 2000 in New York. Approval will be included in the Notice of Grant Award letter to be sent to the Department of Health at a later date.

3.4.3 Outcome Measures

As required, this information is contained in Form 12. In addition to the National Outcome Measures, Puerto Rico has included one State Outcome Measure. A detailed sheet for the State outcomes is also included on Form 16.

TABLE 16

PR Performance Measure	Why was it chosen?	Relationship to Priority Needs	Primary Level	Relationship to outcome measure
1. Number of HIV positive women treated with AZT.	Prevalence of infection. Possibility of prevention. Public Policy. Services are available	No. 1 and 8	DS	Reduce infant mortality. Reduce maternal mortality. Reduce child deaths.
2. Home Visiting Program.	Program refocus under HCR. Availability of personnel. High proportion of pregnant women and children at risk. Healthy Start support.	No. 3, 4, 6, and 8	ES	Infant and maternal mortality.
3. Rate of NTD's.	High prevalence: 2 times higher than US. Increased morbidity and mortality.	No. 7	PB	Infant, perinatal, neonatal and post neonatal mortality
4. Surveillance System of NTD's.	To evaluate the Folic Acid Campaign. As baseline for the surveillance of other birth defects.	No. 3, 7	IB	Infant mortality
5. To determine the prevalence of high risk factors among pregnant women.	Impact on the upward trend of LBW.	No. 7, 3, 8	PB	Infant mortality
6. Birth rate to adolescents 10-14 years old	Serious problem in PR. Priority of the Administration. Nearly 400 cases per year.	No. 5	PB	Maternal and infant mortality rates
7. Rate of deaths from bronchial asthma	High prevalence and mortality in children in PR.	No. 9	PB	Child deaths
8. Standards of Care for CSHCN	Exist for some conditions but need to be revised. Essential in the managed care environment.	No. 10	IB	Child deaths Infant mortality

IV. REQUIREMENTS FOR THE ANNUAL PLAN [Sec. 505 (a), (2)(A)]

The annual plan is guided by the priority needs identified through the needs assessment process, legislative mandates, the National and State performance measures, the health status indicators and of course, the capacity and resources available at the Department of Health.

The table format of the annual plan demonstrates the relationship among priority needs, the level and type of services, as well as the performance and outcome measures intended to be accomplished with each activity. The plan includes activities aimed at improving the health of women of reproductive age, mothers, infants, children, adolescents and children with special health care needs (CSHCN).

Figure 10 presents a summary of services available for the MCH population by levels of the pyramid. **Figure 26** shows the relationship of priority needs and programs in relation to National and State 5-year performance and outcome measures.

TABLE 17
REQUIREMENT FOR THE ANNUAL PLAN FOR THE MCH AND CSHCN PROGRAMS
2000-2001

4.1 Program Activities Related to Performance Measures

Priority Need	Program Activities	Level of Service / Type of Service	Performance Measures	Outcome Measures
1. To reduce infant, children and maternal morbidity and mortality.	1.1 To promote comprehensive prenatal care without co-payment through the GIP to all WCBA less than 200% poverty level.	Direct Health Care Services / Capacity	NPM #5, 12	NOM 1, 2, 3, 4 SOM 1
	1.2 To provide EPSDT services to all infants, children and adolescents under 200% poverty level. Well-child care up to 2 years old and immunization will be provided without co-payment.	Direct Health Care Services / Capacity	NPM #7	NOM #5
	1.3 In collaboration with the Department of Education, conduct a survey of a representative sample of school age children to assess the utilization of EPSDT Services covered by the GIP.		SPM #3	
	1.4 To complement services not covered by the GIP: e.g. contraceptive methods, hearing devices, medical surgical material such as foley and suction catheters, braces, orthoses and prostheses for CSHCN.	Direct Health Care Services / Capacity	NPM#2, 10, 12, 16	NOM 1, 2, 3, 4 SOM 1
	1.5 In collaboration with the Pediatric AIDS program, continue our efforts to assure that all pregnant women receive counseling for HIV screening, testing, and treatment of those found positive on a voluntary basis.	Direct Health Care Services / Risk Factor	SPM #1	NOM 1, 2, 3, 4 SOM 1

Priority Need	Program Activities	Level of Service / Type of Service	Performance Measures	Outcome Measures
	1.6 To screen all newborns for congenital hereditary conditions such as hypothyroidism, sickle cell anemia, PKU and Galactosemia. Refer for nutritional management and follow up.	Population-Based Services / Risk Factor	NPM #4	NOM 1, 2, 3, 4
	1.7 Refer children diagnosed with genetic and metabolic disorders to the Pediatric Habilitative Centers for the specialized and nutritional follow up as required. Includes provision of special formulas to CSHCN ages 5 to 21 years.	Direct Services / Process	NPM #2	NOM 1, 2, 3, 4
	1.8 To continue the planning stage for the development of the universal newborn hearing screening.	Population-Based Services / Risk Factor	NPM#10	
	1.9 To implement the Home Visiting Program in the municipality of San Juan.	Enabling Services/ Process	SPM #2	NOM 1, 2, 3, 4, 5 SOM 1
	1.10 Refer pregnant women and infants identified with nutritional risk factors during the home visit or other outreach activities to the WIC program.	Enabling Services/ Process	SPM 16	NOM 1, 2, 3, 4, 5 SOM 1
	1.11 Refer infants and toddlers identified by the home visiting nurses as suspicious of having developmental delay to the EIP for evaluation, IFSP and provision of services to eligible children.	Direct Services / Risk Factor	NPM #2 SPM #2	

Priority Need	Program Activities	Level of Service / Type of Service	Performance Measures	Outcome Measures
	1.12 Provide postpartum education stressing the following issues: a. Back to sleep position b. The importance of the infant car seat c. Follow-up to the results of the neonatal screening d. The importance of the post partum visit e. The importance of well-baby check-ups and immunizations f. The importance of family planning g. The importance of breastfeeding h. Promote folic acid consumption i. Violence prevention j. Others.	Enabling Services/ Risk Factors	SPM 3	NOM 1, 2, 3, 4, 5 SOM 1
	1.13 Finish the case control study of LBW to identify contributing risks factors and develops an action plan according to the findings.	Infrastructure Building Services/ Risk Factors	SPM 16, 17	NOM 1, 2, 3, 4
	1.14 To expand stakeholders to PR Asthma Coalition and increase the number of referrals to the program according to the established Working Plan.		SPM#7	

Priority Need	Program Activities	Level of Service / Type of Service	Performance Measures	Outcome Measures
2. To increase availability and access to preventive and primary health care services for the MCH population, including CSHCN.	2.1 Disseminate the public policy established by the Secretary of the Department of Health and the Executive Director of ASES, which requires that every pregnant woman be admitted into prenatal care as soon as she requests the services.	Infrastructure Building Services/ Capacity	NPM 18	NOM 1, 2, 3, 4, 5 SOM 1
	2.2 Identify barriers to prenatal care, EPSDT services and immunizations and act accordingly.	Infrastructure Building Services/ Capacity	NPM 5, 7	NOM 1, 2, 3, 4, 5 SOM 1
	2.3 Promote the utilization of early and continuous prenatal care, family planning services and EPSDT through a wide array of activities. These include, but are not limited to: • Public Service Announcements • Outreach activities through dissemination of printed information, posters, health fairs, group orientation, and through the Home Visiting Program.	Enabling Services/ Risk Factor	NPM 18	NOM 1, 2, 3, 4, 5 SOM 1
	2.4 Continue the promotion of the toll-free line, 1-877-641-2004.	Enabling Services/ Capacity	NPM #3	
	2.5 Increase public awareness of services for CSHCN through a wide array of activities.	Population based.	NPM #3	

Priority Need	Program Activities	Level of Service / Type of Service	Performance Measures	Outcome Measures
3. To develop and maintain an MCH infrastructure to adequately assess health needs and to assure the delivery of appropriate and needed services for the MCH population, including CSHCN.	3.1 Continue the improvement of the infrastructure of the MCH/CSHCN programs at the regional levels regarding the availability of computers and needed software, Internet, Email, etc. to reduce the paperwork and expedite communications between central and regional levels.	Infrastructure Building Services/ Capacity	NPM – All SPM – All	All
	3.2 Enhance the skills of the regional staff in computers.	Infrastructure Building Services/ Capacity	NPM - All SPM – All	
	3.3 Identify sources of data needed to monitor performance measures, outcome measures and health indicators for which we are having difficulty in obtaining the data.	Infrastructure Building Services/ Process	NPM and SPM (All)	All
	3.4 Collaborate in the establishment of linkages with public and private entities involved in the provision of services to CSHCN population 0-21 yrs., to share pertinent data.	Infrastructure Building Services/ Capacity	NPM #2, 3, 11, 14 SPM	
	3.5 Establish a cost-effective billing collection system for the reimbursement of payment for services provided at Pediatric Health Centers, and reinvestment for identified needs.	Infrastructure Building Services/ Process	NPM All SPM All	
	3.6 Improve the database system to facilitate the ongoing assessment of MCH needs.	Infrastructure Building Services/ Process	NPM All SPM All	NOM – All SOM #1

Priority Need	Program Activities	Level of Service / Type of Service	Performance Measures	Outcome Measures
	3.7 Analyze collected data.	Infrastructure Building Services/ Process	NPM and SPM	All NOM and SOM 1
	3.8 Continue the elaboration of standards of care for the most common conditions among CSHCN seen at Pediatric Centers.	Infrastructure Building Services/ Capacity	SPM #8	
	3.9 Revise standards of care for adolescent health and services to CSHCN according to the latest recommendations of ACOG, AAP and federal programs.	Infrastructure Building Services/ Capacity	NPM #5, 7, 10, 16, 17, 18 SPM #1	NOM – All SOM 1
	3.10 Disseminate the developed guidelines to primary providers through ASES and the insurance companies.	Infrastructure Building Services/ Process	Same as above.	NOM 1, 2, 3, 4 SOM 1
	3.11 Support and expand resources for the existing Birth Defect Registry to include cleft lip and palate and other birth defects. Promote planning for an Information System Unit encompassing newborn congenital hereditary screening, NTD, Cleft Lip/Palate and universal hearing screening.	Infrastructure Building Services/ Process	SPM #3, 4,10	NOM – All SOM 1
	3.12 Promote prenatal care chart audits by ASES and health insurance companies to identify compliance with established standards of care. An instrument for this purpose has already been designed and submitted to ASES.	Infrastructure Building Services/ Process	NPM #5, 7, 10, 16, 17, 18 SPM #1	NOM 1, 2, 3, 4 SPM #1

Priority Need	Program Activities	Level of Service / Type of Service	Performance Measures	Outcome Measures
	3.13 Monitor perinatal system by tracking selected birth outcomes and share the information with concerned stakeholders. A tool called the Integrated Index of Maternal-Infant Health Status by municipality was developed towards this purpose.	Infrastructure Building Services/Process	NPM #4, 15, 16, 17, 18	NOM 1, 2, 3, 4
4. To improve collaboration among public, private and community based organizations to further program coordination and integration of services.	4.1 Revise MOU's and update those that require changes according to system changes that have occurred during the last 4 years at the Departments of Education, Health and the Family. 4.2 Continue the participation of the MCH staff in different coalitions, interagency committees and task forces. 4.3 Provide technical assistance to Child Care Centers by recently trained staff in our Train the Trainer Team.	Infrastructure Building Services/Process Infrastructure Building Services/Capacity		

Priority Need	Program Activities	Level of Service / Type of Service	Performance Measures	Outcome Measures
	4.4 Update program services and their requirements for MCH/CSHCN and share information with providers on an ongoing basis (primary providers, home visiting nurses and outreachers).	Infrastructure Building Services/ Process	NPM # 3	
	4.5 Increase the participation and collaboration with different entities, committees and coalitions that address the suicide issue among adolescents.	Infrastructure Building Service Capacity.	NPM # 15	NOM # 6
	4.6 Increase family participation in advisory and interagency committees, task forces, staff positions and activities related to the MCH plan.		NPM #14	
5. To reduce unwanted adolescent pregnancies.	5.1 Enroll identified pregnant teens into the Home Visiting Program.	Enabling Service / Risk Factor	SPM 2	NOM 1, 2, 3, 4 SOM 1
	5.2 Provide orientation about the importance of family planning services and how to obtain them after delivery to prevent a repeat pregnancy.	Enabling Service / Risk Factor	NPM #6 SPM 6	NOM 1, 2, 3, 4 SOM 1
	5.3 Continue the implementation of the Abstinence Education Only Program in conjunction with the Department of Education. Provide the "Sex Can Wait" curriculum to at least 100,000 students during FY 2000-2001.	Population Based Services / Risk Factor	NPM 6 SPM 6	NOM 1, 2, 3, 4 SOM 1

Priority Need	Program Activities	Level of Service / Type of Service	Performance Measures	Outcome Measures
	5.4 Support students trained as health promoters in their work with other students.	Population Based Services / Risk Factor	NPM 6 SPM 6	NOM – All SOM 1
	5.5 Provide adolescent pregnancy prevention educational activities as requested by schools, community programs or other concerned groups.	Population Based Services / Risk Factor	NPM 6 SPM 6	NOM 1, 2, 3, 4 SOM 1
	5.6 Disseminate culturally appropriate educational materials concerning the issue of adolescent pregnancy.	Population Based Services / Risk Factor	NPM 6 SPM 6	NOM 1, 2, 3, 4 SOM 1
	5.7 Include CSHCN and families in all activities related to this priority need, in collaboration with the CSHCN program.	Infrastructure Building Services/ Process	NPM 6 SPM 6	NOM 1, 2, 3, 4 SOM 1
	5.8 Train religious leaders to increase their capacity and commitment to develop programs addressing the health issues that affect the adolescent population (e.g. adolescent pregnancy).	Infrastructure Building Services/ Risk Factor	NPM 6 SPM 6	NOM 1, 2, 3, 4 SOM 1
	5.9 Start a school-based education and orientation project geared to pregnant teens in conjunction with the Social Program of the Department of Education.	Enabling service Risk Factor.	NPM # 6 SPM # 6	NOM # 1, 2, 3, 4 SOM # 1

Priority Need	Program Activities	Level of Service / Type of Service	Performance Measures	Outcome Measures
	5.10 Provide training on sex education to parents of school age children.	Enabling Service Risk Factor	NPM #6 SPM #6	NOM 1, 2, 3, 4
6. To reduce unintentional injuries among infants, children and adolescents, including CSHCN.	6.1 Promote the utilization of the infant seat and child restraint through family anticipatory guidance, dissemination of educational materials, health fairs and others.	Population Based Services / Risk Factor	NPM 8	NOM 3, 5
	6.2 Inform families with limited resources about local programs which rent infant car seats.	Enabling Services/ Process	NPM 8	NOM 3
	6.3 Discourage the use of the infant walker.	Population Based Services / Risk Factor		NOM 3
	6.4 Disseminate the Security Check list aimed at prevention of the 10 most common unintentional injuries.	Population Based Services / Risk Factor	NPM # 8	NOM 1, 2, 3, 4, 5
	6.5 Participate in programs regarding injury prevention in local radio and TV.	Population Based Services / Risk Factor	NPM # 8	NOM 3, 5
	6.6 In collaboration with the Office of the First Lady (Our Children First) train child care staff on injury prevention at child care centers.	Population Based Services / Risk Factor	NPM #8	NOM 3, 5

Priority Need	Program Activities	Level of Service / Type of Service	Performance Measures	Outcome Measures
7. To increase awareness regarding MCH issues among health professionals and the public at large.	7.1 Disseminate among concerned individuals and organizations the findings of the surveillance of infant mortality, the study of C-sections, maternal mortality and others.	Infrastructure Building Services/ Capacity	SPM 16, 17, 18	NOM – All SOM 1
	7.2 Develop and implement the initiative "I want to be your partner". A fact sheet covering different topics is being prepared to reach out primary providers by mail.			
	7.3 Identify and evaluate printed educational material to assure that these are culturally appropriate and convey the right message.	Population Based / Process	Several	NOM - All
	7.4 To provide a one day training to the Medicaid personnel aimed at enhancing their knowledge regarding normal adolescent behaviors and sensitivity to their needs during the interview.	Infrastructure Building Services / Capacity		

Priority Need	Program Activities	Level of Service / Type of Service	Performance Measures	Outcome Measures
8. To prevent and reduce behavioral risk factors such as smoking, alcohol consumption and substance abuse among teens and pregnant women.	8.1 Provide continuing education to primary providers and Home Visiting Nurses, including skills for universal screening of alcohol, tobacco, illicit drug use and domestic violence during pregnancy.	Infrastructure Building Services / Risk Factor	SPM 2, 3	NOM 1, 2, 4 SOM # 1
	8.2 Disseminate appropriate culturally sensitive educational materials covering topics such as the effects of smoking, alcohol consumption and illicit drug use during pregnancy. Public awareness geared towards increased risk for congenital anomalies associated to teen pregnancy.	Population Based Services / Risk Factor	SPM 3	NOM # 1, 2, 4 SOM # 1
	8.3 Conduct a survey to determine the prevalence of behavioral risk factors during pregnancy and share information with concerned individuals. (Estudio de Salud Materno Infantil).	Infrastructure Building Services / Process	SPM 5	NOM # 1, 2, 4 SOM # 1
	8.4 Include the topics of alcohol, tobacco, and drug use and violence prevention in patient orientations.	Population Based Services / Risk Factor	SPM 3	NOM 1, 2, 4 SOM #1
	8.5 Provide training for school staff, health professional and others regarding adolescent health problems.	Infrastructure Building Services / Risk Factor	NPM 6, 8, 15 SPM 6	NOM 5
	8.6 Train adolescents as health promoters in 8 public schools.	Enabling Services / Risk Factor	NPM # 6, 8, 15 SPM 6	NOM # 6

Priority Need	Program Activities	Level of Service / Type of Service	Performance Measures	Outcome Measures
9. To diminish morbidity and mortality rates due to bronchial asthma.	9.1 In collaboration with other key players the DOH, implemented the Asthma Coalition; pilot project started in Bayamón. The program includes the following components: a. Identification of severe asthma patients 1-14 years of age in collaboration with insurance companies and refer them to the Pediatric Pulmonary Laboratory at the Cardiovascular Center for evaluation, education of the child, the family and the primary physician regarding appropriate management of the condition according to 1997 NIH standards of care. b. Establishment of an epidemiological surveillance system. c. Collaboration of insurance companies, DOH, Cardiovascular Center of PR, pharmaceutical companies, ASES, UPR School of Medicine and Ponce School of Medicine for the implementation of Work Action Plan geared to reduction of morbi-mortality due to Bronchial Asthma.	Direct Health Care Services / Capacity	SPM #7	NOM 6

Priority Need	Program Activities	Level of Service / Type of Service	Performance Measures	Outcome Measures
10. To enhance competency of the primary care providers to better serve the at-risk MCH population.	10.1 In conjunction with the health insurance companies, provide continuing education activities addressing issues related to: • Maternal and infant health. • Adolescent health. • Benefits of human milk and breastfeeding. • Folic acid supplementation as a strategy to reduce NTD's with emphasis on women at the extremes of the reproductive age (< 20 + >40). • Prevalence of risk behaviors such as use and abuse of tobacco, alcohol and illicit drugs. • Need for universal screening of HIV and intervention during the prenatal period. • The importance of appropriate documentation of vital records: births and death certificates. • Discussion of prenatal and EPSDT standards of care as well as standards of care for CSHCN. • Case coordination for CSHCN. • Identification of CSHCN – Definition. • Early Intervention. • Medical home for CSHCN and family centered services. • Universal Hearing screening. • Provide two training sessions on adolescent health to an interdisciplinary team of health professionals (Train the trainers curriculum). • Others.	Infrastructure Building Services / Risk Factor	NPM – All SPM - All	NOM – All SOM 1

4.2 Other Program Activities

Since 1998, the services of the toll-free information line are being provided through Computer Phone. This private company has integrated all the information/hotlines of the Agency. The service is available 24 hours a day. Monthly reports documenting the number of services provided are submitted to the program. The new number is 1-877-641-2004. The number of calls has increased dramatically through this new system.

The WIC, Medicaid/CHIP and MCH Programs developed a written agreement in February 1998. The programs are working collaboratively as stated in that MOU. By August 2000, a total of 15 LPN's will be paid with CHIP funds to conduct outreach aimed at assuring that children have a health insurance in PR. In addition, they will participate in health promotion activities under the supervision of the MCH Regional Directors.

In addition, the program staff at all levels will be coordinating services with multiple agencies and organizations serving the same target population. Special emphasis will be given to enhancing the coordinating mechanisms with the health insurance companies.

4.3 Public Input [Sec 505 (9) (5) (F)]

During the process of the Block Grant development, public input was requested through advertisements in two islandwide newspapers of wide circulation (**Appendix 7**). No one requested to revise the documents. However, input was obtained through meetings with the MCH Advisory Committee and the participation in interagency committees and coalitions where MCH issues are discussed. The input from families of CSHCN was obtained through focus groups conducted by the SSDI coordinator and the evaluator of CSHCN program.

4.4 Technical Assistance [Sec 509 (a) (4)]

Please refer to Form 15.

V. Supporting Documents

Figures one to 26.

This document contains the requirement for the corresponding FY Application 2000-2001 and the Annual Report for the FY 1998-99.

5.1 Glossary

Administration of Title V Funds - The amount of funds the State uses for the management of the Title V allocation. It is limited by statute to 10 percent of the Federal Title V allotment.

Assessment - (see 'Needs Assessment')

Capacity - Program capacity includes delivery systems, workforce, policies, and support systems (e.g., training, research, technical assistance, and information systems) and other infrastructure needed to maintain service delivery and policy-making activities. Program capacity results measure the strength of the human and material resources necessary to meet public health obligations. As program capacity sets the stage for other activities, program capacity results are closely related to the results for process, health outcome, and risk factors. Program capacity results should answer the question, 'What does the State need to achieve the results we want?'

Capacity Objectives - Objectives that describe an improvement in the ability of the program to deliver services or affect the delivery of services.

Care Coordination Services for CSHCN - Those services that promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for children with special health care needs and their families. *[Title V Sec. 501(b)(3)*]

Carryover (as used in Forms 2 and 3) - The unobligated balance from the previous year's MCH Block Grant Federal Allocation.

Case Management Services - For pregnant women - those services that assure access to quality prenatal, delivery and postpartum care. For infants up to age one - those services that assure access to quality preventive and primary care services. *[Title V Sec. 501(b)(4)]*

Children -A child from 1st birthday through the 21st year, who is not otherwise included in any other class of individuals.

Children With Special Health Care Needs (CSHCN) - ***(For budgetary purposes)*** Infants or children from birth through the 21st year with special health care needs who the State has elected to provide with services funded through Title V. CSHCN are children who have health problems requiring more than routine and basic care including children with or at risk of disabilities, chronic illnesses and conditions and health-related education and behavioral problems. ***(For planning and systems development)*** Those children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.

Children With Special Health Care Needs (CSHCN) - Constructs of a Service System

1. State Program Collaboration with Other State Agencies and Private Organizations

States establish and maintain ongoing interagency collaborative processes for the assessment of needs with respect to the development of community-based systems of services for CSHCN. State programs collaborate with other agencies and organizations in the formulation of coordinated policies, standards, data collection and analysis, financing of services, and program monitoring to assure comprehensive, coordinated services for CSHCN and their families.

2. State Support for Communities

State programs emphasize the development of community-based programs by establishing and maintaining a process for facilitating community systems building through mechanisms such as technical assistance and consultation, education and training, common data protocols, and financial resources for communities engaged in systems development, to assure that the unique needs of CSHCN are met.

3. Coordination of Health Components of Community-Based Systems

A mechanism exists in communities across the State for coordination of health services with one another. This includes coordination among providers of primary care, Habilitative and rehabilitative services, other specialty medical treatment services, mental health services, and home health care.

4. Coordination of Health Services with Other Services at the Community Level

A mechanism exists in communities across the State for coordination and service integration among programs serving CSHCN, including early intervention and special education, social services, and family support services.

Classes of Individuals - Authorized persons to be served with Title V funds. See individual definitions under 'Pregnant Women,' 'Infants,' 'Children with Special Health Care Needs,' 'Children,' and 'Others.'

Community - A group of individuals living as a smaller social unit within the confines of a larger one due to common geographic boundaries, cultural identity, a common work environment, common interests, etc.

Community-based Care - Services provided within the context of a defined community.

Community-based Service System - An organized network of services that are grounded in a plan developed by a community and that is based upon needs assessments.

Coordination (see Care Coordination Services)

Culturally Sensitive - The recognition and understanding that different cultures may have different concepts and practices with regard to health care; the respect of those differences and the development of approaches to health care with those differences in mind.

Culturally Competent - The ability to provide services to clients that honor different cultural beliefs, interpersonal styles, attitudes and behaviors and the use of Multi cultural staff in the policy development, administration and provision of those services.

Deliveries - Women who received a medical care procedure associated with the delivery or expulsion of a live birth or fetal death (gestation of 20 weeks or greater).

Direct Health Services - Those services generally delivered one-on-one between a health professional and a patient in an office, clinic or emergency room which may include primary care physicians, registered dietitians, public health or visiting nurses, nurses certified for obstetric and pediatric primary care, medical social workers, nutritionists, dentists, sub-specialty physicians who serve children with special health care needs, audiologists, occupational therapists, physical therapists, speech and language therapists, specialty registered dietitians. Basic services include what most consider ordinary medical care: inpatient and outpatient medical services, allied health services, drugs, laboratory testing, x-ray services, dental care, and pharmaceutical products and services. State Title V programs support - by directly operating programs or by funding local providers - services such as prenatal care, child health including immunizations and treatment or referrals, school health and family planning. For CSHCN, these services include specialty and subspecialty care for those with HIV/AIDS, hemophilia, birth defects, chronic illness, and other conditions requiring sophisticated technology, access to highly trained specialists, or an array of services not generally available in most communities.

Enabling Services - Services that allow or provide for access to and the derivation of benefits from, the array of basic health care services and include such things as transportation, translation services, outreach, respite care, health education, family support services, purchase of health insurance, case management, coordination with Medicaid, WIC and education. These services are especially required for the low income, disadvantaged, geographically or culturally isolated, and those with special and complicated health needs. For many of these individuals, the enabling services are essential - for without them access is not possible. Enabling services most commonly provided by agencies for CSHCN include transportation, care coordination, translation services, home visiting, and family outreach. Family support activities include parent support groups, family training workshops, advocacy, nutrition and social work.

Family-centered Care - A system or philosophy of care that incorporates the family as an integral component of the health care system.

Federal (Allocation) (as it applies specifically to the Application Face Sheet [SF 424] and Forms 2 and 3) -The moneys provided to the States under the Federal Title V Block Grant in any given year.

Government Performance and Results Act (GPRA) - Federal legislation enacted in 1993 that requires Federal agencies to develop strategic plans, prepare annual plans setting performance goals, and report annually on actual performance.

Health Care System - The entirety of the agencies, services, and providers involved or potentially involved in the health care of community members and the interactions among those agencies, services and providers.

Infants - Children under one year of age not included in any other class of individuals.

Infrastructure Building Services - The services that are the base of the MCH pyramid of health services and form its foundation are activities directed at improving and maintaining the health status of all women and children by providing support for development and maintenance of comprehensive health services systems including development and maintenance of health services standards/guidelines, training, data and planning systems. Examples include needs assessment, evaluation, planning, policy development, coordination, quality assurance, standards development, monitoring, training, applied research, information systems and systems of care. In the development of systems of care it should be assured that the systems are family centered, community based and culturally competent.

Local Funding (as used in Forms 2 and 3)-Those moneys deriving from local jurisdictions within the State that are used for MCH program activities.

Low Income - An individual or family with an income determined to be below the income official poverty line defined by the Office of Management and Budget and revised annually in accordance with section 673(2) of the Omnibus Budget Reconciliation Act of 1981. *[Title V, Sec. 501 (b)(2)]*

MCH Pyramid of Health Services - (see 'Types of Services')

Measures - (see 'Performance Measures')

Needs Assessment - A study undertaken to determine the service requirements within a jurisdiction. For maternal and child health purposes, the study is aimed at determining:

1) What is essential in terms of the provision of health services;
2) What is available, and
3) What is missing.

Objectives - The yardsticks by which an agency can measure its efforts to accomplish a goal. (See also 'Performance Objectives')

Other Federal Funds (Forms 2 and 3) - Federal funds other than the Title V Block Grant that is under the control of the person responsible for administration of the Title V program. These may include, but are not limited to: WIC, EMSC, Healthy Start, SPRANS, AIDS moneys, CISS funds, MCH targeted funds from CDC and MCH Education funds.

Others (as in Forms 4, 7, and 10) - Women of childbearing age, over age 21, and any others defined by the State and not otherwise included in any of the other listed classes of individuals.

Outcome Objectives - Objectives that describe the eventual result sought, the target date, the target population, and the desired level of achievement for the result. Outcome objectives are related to health outcome and are usually expressed in terms of morbidity and mortality.

Outcome Measure - The ultimate focus and desired result of any set of public health program activities and interventions is an improved health outcome. Morbidity and mortality statistics are indicators of achievement of health outcome. Health outcome results are usually longer term and tied to the ultimate program goal. Outcome measures should answer the question, 'Why does the State do our program?'

Performance Indicator - The statistical or quantitative value that expresses the result of a performance objective.

Performance Measure - A narrative statement that describes a specific maternal and child health need, or requirement, that, when successfully addressed, will lead to, or will assist in leading to, a specific health outcome within a community or jurisdiction and generally within a specified time frame. (Example: 'The rate of women in [State] who receive early prenatal care in 19__.' This performance measure will assist in leading to [the health outcome measure of] reducing the rate of infant mortality in the State).

Performance Measurement - The collection of data on, recording of, or tabulation of results or achievements, usually for comparing with a benchmark.

Performance Objectives - A statement of intention with which actual achievement and results can be measured and compared. Performance objective statements clearly describe what is to be achieved, when it is to be achieved, the extent of the achievement, and target populations.

Population Based Services - Preventive interventions and personal health services, developed and available for the entire MCH population of the State rather than for individuals in a one-on-one situation. Disease prevention, health promotion, and statewide outreach are major components. Common among these services are newborn screening, lead screening, immunization, Sudden Infant Death Syndrome counseling, oral health, injury prevention, nutrition and outreach/public education. These services are generally available whether the mother or child receives care in the private or public system, in a rural clinic or an HMO, and whether insured or not.

Pregnant Woman - A female from the time that she conceives to 60 days after birth, delivery, or expulsion of fetus.

Preventive Services - Activities aimed at reducing the incidence of health problems or disease prevalence in the community, or the personal risk factors for such diseases or conditions.

Primary Care - The provision of comprehensive personal health services that include health maintenance and preventive services, initial assessment of health problems, treatment of uncomplicated and diagnosed chronic health problems, and the overall management of an individual's or family's health care services.

Process - Process results are indicators of activities, methods, and interventions that support the achievement of outcomes (e.g., improved health status or reduction in risk factors). A focus on process results can lead to an understanding of how practices and procedures can be improved to reach successful outcomes. Process results are a mechanism for review and accountability, and as such, tend to be shorter term than results focused on health outcomes or risk factors. The utility of process results often depends on the strength of the relationship between the process and the outcome. Process results should answer the question, 'Why should this process be undertaken and measured (i.e., what is its relationship to achievement of a health outcome or risk factor result)?'

Process Objectives - The objectives for activities and interventions that drive the achievement of higher-level objectives.

Program Income (as used in the Application Face Sheet [SF 424] and Forms 2 and 3) - Funds collected by State MCH agencies from sources generated by the State's MCH program to include insurance payments, MEDICAID reimbursements, HMO payments, etc.

Risk Factor Objectives - Objectives that describe an improvement in risk factors (usually behavioral or physiological) that cause morbidity and mortality.

Risk Factors - Public health activities and programs that focus on reduction of scientifically established direct causes of, and contributors to, morbidity and mortality (i.e., risk factors) are essential steps toward achieving health outcomes. Changes in behavior or physiological conditions are the indicators of achievement of risk factor results. Results focused on risk factors tend to be intermediate term. Risk factor results should answer the question, 'Why should the State address this risk factor (i.e., what health outcome will this result support)?'

State - As used in this guidance, includes the 50 States and the 9 jurisdictions of the District of Columbia, the Government of Puerto Rico, the Virgin Islands, Guam, American Samoa, the Commonwealth of the Northern Mariana Islands, the Republic of the Marshall Islands, the Federated States of Micronesia and the Republic of Belau.

State Funds (as used in Forms 2 and 3) - The State's required matching funds (including overmatch) in any given year.

Systems Development - Activities involving the creation or enhancement of organizational infrastructures at the community level for the delivery of health services and other needed ancillary services to individuals in the community by improving the service capacity of health care service providers.

Technical Assistance (TA) - The process of providing recipients with expert assistance of specific health related or administrative services that include; systems review planning, policy options analysis, coordination coalition building/training, data system development, needs assessment, performance indicators, health care reform wrap around services, CSHCN program development/evaluation, public health managed care quality standards development, public and private interagency integration, and identification of core public health issues.

Title XIX, number of infants entitled to - The unduplicated count of infants who were eligible for the State's Title XIX (MEDICAID) program at any time during the reporting period.

Title XIX, number of pregnant women entitled to - The number of pregnant women who delivered during the reporting period who were eligible for the State's Title XIX (MEDICAID) program

Title V, number of deliveries to pregnant women served under - Unduplicated number of deliveries to pregnant women who were provided prenatal, delivery, or post-partum services through the Title V program during the reporting period.

Title V, number of infants enrolled under - The unduplicated count of infants provided a direct service by the State's Title V program during the reporting period.

Total MCH Funding - All the MCH funds administered by a State MCH program which is made up of the sum of the *Federal* Title V Block Grant allocation, the *Applicant's* funds (carryover from the previous year's MCH Block Grant allocation - the unobligated balance), the *State* funds (the total matching funds for the Title V allocation - match and overmatch), *Local* funds (total of MCH dedicated funds from local jurisdictions within the State), *Other* Federal funds (moneys other than the Title V Block Grant that are under the control of the person responsible for administration of the Title V program), and *Program Income* (those collected by State MCH agencies from insurance payments, MEDICAID, HMO's, etc.).

Types of Services - The major kinds or levels of health care services covered under Title V activities. See individual definitions under 'Infrastructure Building,' 'Population Based Services,' 'Enabling Services,' and 'Direct Medical Services.'

5.2 Assurances and Certifications

See **Appendix** 10

5.3 Other Supporting Documents

See **Appendix** 1,2,3,4,5,6,7,8,9

5.4 Core Health Indicators Forms

See **Appendix 11**

5.5 Core Health Status Indicators Detail Sheets

See **Appendix 11**

5.6 Developmental Health Status Indicators Forms

5.7 Developmental Health Status Indicators Forms Detail Sheets

5.8 All other Forms

5.9 National "Core" Performance Measurements Detail Sheets

5.10 State "Negotiated" Performance Measurements Detail Sheets

5.11 Outcome Measures Detail Sheets.

VI. APPENDICES

Appendix 1:	Map of Municipalities under the HCR.
Appendix 2:	Composition of the MCH Advisory Board.
Appendix 3:	Organizational Chart of the Department of Health
Appendix 4:	Map of Health Regions.
Appendix 5:	Organizational Chart of the Secretariat for Health Promotion and Protection.
Appendix 6:	Home visiting nurses, perinatal nurses and Outreachers Tasks
Appendix 7:	Newspaper Ads.
Appendix 8:	Integrated Index of Maternal Infant Health Status by Municipality
Appendix 9:	Process for Management and Monitorizing of Federal Funds
Appendix 10:	Assurances and Certifications
Appendix 11:	ERP Forms
Appendix 12:	Notes for ERP Forms

ASSURANCES -- NON-CONSTRUCTION PROGRAMS

Note: Certain of these assurances may not be applicable to your project or program. If you have any questions, please contact the Awarding Agency. Further, certain Federal assistance awarding agencies may require applicants to certify to additional assurances. If such is the case, you will be notified.

As the duly authorized representative of the applicant I certify that the applicant:

1. Has the legal authority to apply for Federal assistance, and the institutional, managerial and financial capability (including funds sufficient to pay the non-Federal share of project costs) to ensure proper planning, management and completion of the project described in this application.

2. Will give the awarding agency, the Comptroller General of the United States, and if appropriate, the State, through any authorized representative, access to and the right to examine all records, books, papers, or documents related to the assistance; and will establish a proper accounting system in accordance with generally accepted accounting standards or agency directives.

3. Will establish safeguards to prohibit employees from using their position for a purpose that constitutes or presents the appearance of personal or organizational conflict of interest, or personal gain.

4. Will initiate and complete the work within the applicable time frame after receipt of approval of the awarding agency.

5. Will comply with the Intergovernmental Personnel Act of 1970 (42 U.S.C. Sects. 4728-2763) relating to prescribed standards for merit systems for programs funded under one of the nineteen statutes or regulations specified in Appendix A of OPM's Standards for a Merit System of Personnel Administration (5 C.F.R. 900, Subpart F).

6. Will comply with all Federal statutes relating to non-discrimination. These include but are not limited to (a) Title VI of the Civil Rights Act of 1964 (P.L. 88 Sect. 352) which prohibits discrimination on the basis of race, color or national origin; (b) Title IX of the Education Amendments of 1972, as amended (20 U.S.C. Sects. 1681-1683, and 1685-1686), which prohibits discrimination on the basis of sex; Section 504 of the Rehabilitation Act of 1973, as amended (29 U.S.C. Sect. 794), which prohibits discrimination on the basis of handicaps; (d) The Age Discrimination Act of 1975, as amended (42 U.S.C. Sects 6101 6107), which prohibits discrimination on the basis of age; (e) the Drug Abuse Office of Treatment Act of 1972 (P.L. 92-255), as amended, relating to non-discrimination on the basis of drug abuse; (f) the Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment, and Rehabilitation Act of 1970 (P.L. 91-616), as amended, relating to non-discrimination on the basis of alcohol

abuse or alcoholism; (g) Sects. 523 and 527 of the Public Health Service Act of 1912 (42 U.S.C. Sect. 3601 et seq.), as amended, relating to non-discrimination in the sale, rental, or financing of housing; (I) any other non-discrimination provisions in the specific statute(s) under which application for Federal assistance is being made; and (j) the requirements of any other non-discrimination statute(s) which may apply to the application.

7. Will comply, or has already complied, with the requirements of Titles II and III of the Uniform Relocation Assistance and Real Property Acquisition Policies Act of 1970 (P.L. 91-646) which provide for fair and equitable treatment of persons displaced or whose property is acquired as a result of Federal or federally assisted programs. These requirements apply to all interests in real property acquired for project purposes regardless of Federal participation in purchases.

8. Will comply with the provisions of the Hatch Act (5 U.S.C. Sects 1501-1508 and 7324-7328) which limit the political activities of employees whose principal employment activities are funded in whole or in part with Federal funds.

9. Will comply, as applicable, with the provisions of the Davis-Bacon Act (40 U.S.C. Sects. 276a to 276a-7), the Copeland Act (40 U.S.C. Sect 276c and 18 U.S.C. Sect. 874), the Contract Work Hours and Safety Standards Act (40 U.S.C. Sects. 327-333), regarding labor standards for federally assisted construction subagreements.

10. Will comply, if applicable, with flood insurance purchase requirements of Section 102(a) of the Flood Disaster Protection Act of 1973 (P.L. 93-234) which requires recipients in a special flood hazard area to participate in the program and to purchase flood insurance if the total cost of insurable construction and acquisition is $10,000 or more.

11. Will comply with environmental standards which may be prescribed pursuant to the following: (a) institution of environmental quality control measures under the National Environmental Policy Act of 1969 (P.L. 91-190) and Executive Order (EO) 11514; (b) notification of violating facilities pursuant to EO 11738; protection of wetlands pursuant to EO 11990; (d) evaluation of flood hazards in flood plains in accordance with EO 11988; (e) assurance of project consistency with the approved State management program developed under the Coastal Zone Management Act of 1972 (16 U.S.C. Sects. 1451 et seq.); (f) conformity of Federal actions to State (Clear Air) Implementation Plans under Section 176 of the Clear Air Act of 1955, as amended (42 U.S.C. 7401 et seq.); (g) protection of underground sources of drinking water under the Safe Drinking Water Act of 1974, as amended (P.L. 93-523); and (h) protection of endangered species under the Endangered Species Act of 1973, as amended (P.L. 93-205).

12. Will comply with the Wild and Scenic Rivers Act of 1968 (16 U.S.C. Sects 1271 et seq.) related to protecting components or potential components of the national wild and scenic rivers systems

13. Will assist the awarding agency in assuring compliance with Section 106 of the National Historic Preservation Act of 1966, as amended (16 U.S.C. Sect. 470), EO 11593 (identification and preservation of historic properties), and the Archaeological and Historic Preservation Act of 1974 (16 U.S.C. Sects. 469a-1 et seq.)

14. Will comply with P.L.93-348 regarding the protection of human subjects involved in research, development, and related activities supported by this award of assistance.

15. Will comply with Laboratory Animal Welfare Act of 1966 (P.L. 89-544, as amended, 7 U.S.C. Sects. 2131 et seq.) pertaining to the care, handling, and treatment of warm blooded animals held for research, teaching, or other activities supported by the award of assistance.

16. Will comply with the Lead-Based Paint Poisoning Prevention Act (42 U.S.C. Sects. 4801 et seq.) which prohibits the use of lead based paint in construction or rehabilitation of residence structures.

17. Will cause to be performed the required financial and compliance audits in accordance with the Single Audit Act of 1984.

18. Will comply will all applicable requirements of all other Federal laws, executive orders, regulations and policies governing this program.

CERTIFICATIONS

1. CERTIFICATION REGARDING DEBARMENT AND SUSPENSION

By signing and submitting this proposal, the applicant, defined as the primary participant in accordance with 45 CFR Part 76, certifies to the best of its knowledge and belief that it and its principals:

(a) are not presently debarred, suspended, proposed for debarment, declared ineligible, or voluntarily excluded from covered transactions by any Federal Department or agency;

(b) have not within a 3-year period preceding this proposal been convicted of or had a civil judgment rendered against them for commission or fraud or criminal judgment in connection with obtaining, attempting to obtain, or performing a public (Federal, State, or local) transaction or contract under a public transaction; violation of Federal or State antitrust statutes or commission of embezzlement, theft, forgery, bribery, falsification or destruction of records, making false statements, or receiving stolen property;
are not presently indicted or otherwise criminally or civilly charged by a governmental entity (Federal, State or local) with commission or any of the offenses enumerated in paragraph (b) of the certification; and

(d) have not within a 3-year period preceding this application/proposal had one or more public transactions (Federal, State, or local) terminated for cause or default.

Should the applicant not be able to provide this certification, an explanation as to why should be placed after the assurances page in the application package.

The applicant agrees by submitting this proposal that it will include, without modification, the clause, titled 'Certification Regarding Debarment, Suspension, Ineligibility, and Voluntary Exclusion -- Lower Tier Covered Transactions' in all lower tier covered transactions (i.e. transactions with sub-grantees and/or contractors) in all solicitations for lower tier covered transactions in accordance with 45 CFR Part 76.

2. CERTIFICATION REGARDING DRUG-FREE WORKPLACE REQUIREMENTS

The undersigned (authorized official signing for applicant organization) certifies that the applicant will, or will continue to, provide a drug-free workplace in accordance with 45 CFR Part 76 by:

(a) Publishing a statement notifying employees that the unlawful manufacture, distribution, dispensing, possession or use of a controlled substance is prohibited in the grantee's workplace and specifying the actions that will be taken against employees for violation of such prohibition;

(b) Establishing an ongoing drug-free awareness program to inform employees about-
  (1) The dangers of drug abuse in the workplace;
  (2) The grantee's policy of maintaining a drug-free workplace,
  (3) Any available drug counseling, rehabilitation, and employee assistance programs; and

(4) The penalties that may be imposed upon employees for drug abuse violations occurring in the workplace;

Making it a requirement that each employee to be engaged in the performance of the grant be given a copy of the statement required by paragraph (a) above;

(d) Notifying the employee in the statement required by paragraph (a) above, that, as a condition of employment under the grant, the employee will-

(1) Abide by the terms of the statement; and

(2) Notify the employer in writing of his or her conviction for violation of a criminal drug statute occurring in the workplace no later than five calendar days after such conviction;

(e) Notify the agency in writing within ten calendar days after receiving notice under paragraph (d)(2) from an employee or otherwise receiving actual notice of such conviction. Employers of convicted employees must provide notice, including position title, to every grant officer or other designee on whose grant activity the convicted employee was working, unless the Federal agency has designated a central point for the receipt of such notices. Notice shall include the identification number(s) of each affected grant;

(f) Taking one of the following actions, within 30 calendar days of receiving notice under paragraph (d)(2), with respect to any employee who is so convicted-

(1) Taking appropriate personnel action against such an employee, up to and including termination, consistent with the requirements of the Rehabilitation Act of 1973, as amended, or

(2) Requiring such employee to participate satisfactorily in a drug abuse assistance or rehabilitation program approved for such purposes by a Federal, State, or local health, law enforcement, or other appropriate agency;

(g) Making a good faith effort to continue to maintain a drug-free workplace through implementation of paragraphs (a), (b), (c), (d), (e), and (f).

For purposes of paragraph (e) regarding agency notification of criminal drug convictions, the DHHS has designated the following central point for receipt of such notices:

Division of Grants Policy and Oversight
Office of Management and Acquisition
Department of Health and Human Services
Room 517-D
200 Independence Avenue, S.W.
Washington, D.C. 20201

3. CERTIFICATION REGARDING LOBBYING

Title 31, United States Code, Section 1352, entitled 'Limitation on use of appropriated funds to influence certain Federal contracting and financial transactions,' generally prohibits recipients of Federal grants and cooperative agreements from using Federal (appropriated) funds for lobbying the Executive or Legislative Branches of the Federal Government in connection with a SPECIFIC grant or cooperative agreement. Section 1352 also requires that each person who requests or receives a

Federal grant or cooperative agreement must disclose lobbying undertaken with non-Federal (non-appropriated) funds. The requirements apply to grants and cooperative agreements EXCEEDING $100,000 in total costs (45 CFR Part 93).

The undersigned (authorized official signing for the applicant organization) certifies, to the best of his or her knowledge and belief that:

(1) No Federal appropriated funds have been paid or will be paid, by or on behalf of the undersigned, to any person for influencing or attempting to influence an officer or employee of any agency, a Member of Congress, an officer or employee of Congress, or an employee of a Member of Congress in connection with the awarding of any Federal contract, the making of any Federal grant, the making of any Federal loan, the entering into of any cooperative agreement, and the extension, continuation, renewal, amendment, or modification of any Federal contract, grant, loan, or cooperative agreement.

(2) If any funds other than Federally appropriated funds have been paid or will be paid to any person for influencing or attempting to influence an officer or employee of any agency, a Member of Congress, an officer or employee of Congress, or an employee of a Member of Congress in connection with this Federal contract, grant, loan, or cooperative agreement, the undersigned shall complete and submit Standard Form-LLL, 'Disclosure of Lobbying Activities,' in accordance with its instructions. (If needed, Standard Form-LLL, 'Disclosure of Lobbying Activities,' its instructions, and continuation sheet are included at the end of this application form.)

(3) The undersigned shall require that the language of this certification be included in the award documents for all subawards at all tiers (including subcontracts, subgrants, and contracts under grants, loans, and cooperative agreements) and that all subrecipients shall certify and disclose accordingly.

This certification is a material representation of fact upon which reliance was placed when this transaction was made or entered into. Submission of this certification is a prerequisite for making or entering into this transaction imposed by Section 1352, U.S. Code. Any person who fails to file the required certification shall be subject to a civil penalty of not less than $10,000 and not more than $100,000 for each such failure.

4. CERTIFICATION REGARDING PROGRAM FRAUD CIVIL REMEDIES ACT (PFCRA)

The undersigned (authorized official signing for the applicant organization) certifies that the statements herein are true, complete, and accurate to the best of his or her knowledge, and that he or she is aware that any false, fictitious, or fraudulent statements or claims may subject him or her to criminal, civil, or administrative penalties. The undersigned agrees that the applicant organization will comply with the Public Health Service terms and conditions of award if a grant is awarded as a result of this application.

5. CERTIFICATION REGARDING ENVIRONMENTAL TOBACCO SMOKE

Public Law 103-227, also know as the Pro-Children Act of 1994 (Act), requires that smoking not be permitted in any portion of any indoor facility owned or leased or contracted for by an entity and used routinely or regularly for the provision of health, day care, early childhood development services, education or library services to children under the age of 18 if the services are funded by Federal programs either directly or through State or local governments by Federal grant, contract, loan, or loan guarantee. The law also applies to children's services that are provided in indoor facilities that are constructed, operated, or maintained with such Federal funds. The law does not apply to children's services provided in private residences; portions of facilities used for inpatient drug or alcohol treatment; service providers whose sole source of applicable Federal funds is Medicare or Medicaid; or facilities where WIC coupons are redeemed. Failure to comply with the provisions of the law may result in the imposition of a monetary penalty of up to $1,000 for each violation and/or the imposition of an administrative compliance order on the responsible entity.

By signing this certification, the undersigned certifies that the applicant organization will comply with the requirements of the Act and will not allow smoking within any portion of any indoor facility used for the provision of services for children as defined by the Act.

The applicant organization agrees that it will require that the language of this certification be included in any subawards which contain provisions for children's services and that all subrecipients shall certify accordingly.

The Public Health Service strongly encourages all grant recipients to provide a smoke free workplace and promote the non-use of tobacco products. This is consistent with the PHS mission to protect and advance the physical and mental health of American people.